Youth—Other

Attachment B: System of Care Assessment

# **Youth Stipend Receipt**

Date:		
Project:	CMHS #633430.0.00x.00.001	
Location:		
I,	(Print Name)	_, received \$15.00 for my participation in an
interview fo	r the national evaluation of the Cor	nprehensive Community Health

Services for Children and Their Families Program.

(signature)

Interviewed\_

Interviewer

Assessment #\_\_\_\_

## Informed Consent System of Care Assessment Youth (18–21 years old)

#### Purpose

The (*name of grant program*) in your community provides services to children and youth and their families. The Center for Mental Health Services in the Federal government wants to know more about these services. They want to know how well these services work. The National Evaluation Team is talking to children and youth and their families in (*name of grant program*) to learn more about how to make these services better. I would like to ask you some questions about (*name of grant program*). You will be able to tell me what you think about the program and the services you have received.

This interview will last about 45 minutes. To help you decide if you want to participate in this interview, here are some things to know:

- Your participation is voluntary and completely by your own choice.
- You may choose to stop the interview at any time and for any reason. You also may choose not to answer any of the questions.
- The information you provide to us will be carefully protected. Your name will not be used in any reports from this interview.
- You will receive \$15 in appreciation for meeting with me today.
- We have obtained a Certificate of Confidentiality (CC) from the U.S. Department of Health and Human Services (DHHS) to keep anything that you tell us private. This means that we will not tell anyone what you tell us even if a judge tries to force us to identify you as a person in the study. You should know, however, that we may tell local authorities if harm to you, harm to others, or if child abuse/neglect becomes a concern. Also, the government agency that has provided the money for this project may see your information if they ask for our records to ensure we were conducting the project correctly. The CC that we have does not mean that DHHS approves or disapproves this project.
- You will not get any benefit from participating in the interview. A risk is that you may feel uncomfortable about answering questions about your experiences in *(name of grant program)*.
- I will answer any questions you have about this interview before we begin. If you have questions after the interview is over, you may contact Freda Brashears at ICF Macro, Atlanta, GA. Her toll-free telephone number is 1-866-368-5657.

## **Voluntary Consent**

I read this form or it has been read to me. I understand what it says. My questions (if any) have been answered. A copy of this form will be given to me. By signing my name below, I freely agree to participate in this interview.

Participant Printed Name		
Participant Signature		
Witness	Date	

Interviewer\_\_\_\_\_

Interviewed

Assessment #\_\_\_\_

## Informed Assent System of Care Assessment Youth (14–17 Years Old)

The <u>(name of grant program)</u> in your community provides services to children and youth and their families. The Center for Mental Health Services in the federal government wants to know more about these services. They want to know how well these services work. The National Evaluation Team is talking to children and youth and their families in <u>(name of grant program)</u> to learn more about how to make these services better. I would like to ask you some questions about <u>(name of grant program)</u>. You will be able to tell me what you think about the program and the services you have received.

This interview will last about 45 minutes. To help you decide if you want to participate in this interview, here are some things to know:

- Your participation is voluntary and completely by your own choice.
- You may choose to invite your parent or caregiver to sit in on the interview.
- You may choose to stop the interview at any time and for any reason. You also may choose not to answer any of the questions.
- The information you provide to us will be carefully protected. Your name will not be used in any reports from this interview.
- You will receive \$15 in appreciation for meeting with me today.
- We have obtained a Certificate of Confidentiality (CC) from the U.S. Department of Health and Human Services (DHHS) to keep anything that you tell us private. This means that we will not tell anyone what you tell us even if a judge tries to force us to identify you as a person in the study. You should know, however, that we may tell local authorities if harm to you, harm to others, or if child abuse/neglect becomes a concern. Also, the government agency that has provided the money for this project may see your information if they ask for our records to ensure we were conducting the project correctly. The CC that we have does not mean that DHHS approves or disapproves this project.
- You will not get any benefit from participating in the interview. A risk is that you may feel uncomfortable about answering questions about your experiences in *(name of grant program)*.
- I will answer any questions you have about this interview before we begin. If you have questions after the interview is over, you may contact Freda Brashears at ICF Macro, Atlanta, GA. Her toll-free telephone number is 1-866-368-5657.

#### **Voluntary Assent**

I read this form or it has been read to me. I understand what it says. My questions (if any) have been answered. A copy of this form will be given to me. By signing my name below, I freely agree to participate in this interview.

Participant Printed Name	
Participant Signature	
Witness	Date

Attachment E: Sector and Comparison Study

## EDUCATION SECTOR AND COMPARISON STUDY INFORMED ASSENT—YOUTH VERSION

## Purpose

The Center for Mental Health Services (CMHS), a center in the Substance Abuse and Mental Health Services Administration, an agency within the United States Department of Health and Human Services, is studying system of care programs. The Center for Mental Health Services (CMHS) wants to know more about educational, mental health, substance use, and other behavioral services provided to children and their families. They want to know how well these services work. ICF Macro is conducting a study to learn more about how to make these services better by talking to children and families in the (**agency name/system name**).

The person who takes care of you is being asked questions for this study, and may have also answered questions in the past. Because you are 11 years old, we would like to ask you questions. You will be able to tell us about yourself and what you think about your services.

## **Description of Participation**

You will have an interview every 6 months. You may have up to five interviews. We can talk with you in your home or any other place that is best for you. Each interview will take about 1 hour.

You will be asked questions about how you feel. You will be asked about what you do at home, in school, and in your neighborhood. You will be asked about what you do with your family and friends. You will be asked about the services you have had. We will still ask to talk to you if you stop getting services.

We would like you to let us look at your records. These records include your grades, how much you were absent, and if you were ever in detention. We may also want to look at records about your services from other agencies where you may have received services. We will also want to talk to people who work at your school.

## **Risks and Benefits**

You will not get any benefits from being in this study. You may learn new things about yourself. As a result of this study, services for youth, like the ones you receive, may get better. A risk is that you may feel uncomfortable about answering questions about yourself. We have taken steps to protect your privacy.

## Compensation

You will receive \$20 for each interview you complete, and a \$50 bonus at the end of the 24month period if you complete all 5 waves of data collection, to thank you for your time.

## **Protection of Information**

The study team has taken steps to protect your privacy. The information obtained in your interviews and your record review will be used for this study. Only authorized people will have access to the information. None of the interview or record review forms that are used in the study

have your name on them. They only have special codes. Papers with your name on them will be kept in a locked filing cabinet. In reports, your answers will be grouped with those of others. We will never mention your name. The information obtained in your interviews will be released to the national evaluation team, consisting of ICF Macro, and our funding agency, the Substance Abuse and Mental Health Services Administration.

There are two instances when the study team will not be able to keep your information confidential. If a study team member finds out that you plan to harm yourself or someone else or if there is alleged or suspected child abuse or neglect, we may report it to local authorities.

Also, we have applied for a Confidentiality Certificate from the Federal government to protect the people who interview you from being forced, even under a court order or subpoena, to identify you. The Confidentiality Certificate does not imply that the government has approved or disapproved of this study. In addition, the Federal agency funding this research may see your information if it audits us to ensure that the study team protects your rights and safety.

## **Rights Regarding Decision to Participate**

It is completely up to you whether you participate in the study. If you agree to take part in this study, you can change your mind and quit at any time. If you change your mind and quit, any information you gave to the study will be destroyed, if this is what you want. If you decide not to be in this study, it will not affect services for you or your family. You should also know that if you decide to participate now and later change your mind, you can withdraw from the study at any time.

## **Contact Information**

If you have any questions about this evaluation study, you can call (*Research Coordinator*) to have your questions answered. You can call him/her collect at (555) 555–5555. To contact the Institutional Review Board that reviewed this study you can call 1-877-556-2218.

## **Voluntary Assent**

I have read this form or, it has been read to me, and I understand what it says. My questions have been answered. A copy of this form will be given to me.

By signing my name below, I freely agree to the following as indicated by a check in the YES box.

1. To be interviewed at the beginning of the study and every 6 months thereafter, for up to 24 months.

Yes
No

2. To have a study team member contact my school teacher and head of my school to be interviewed for the study.

Yes
No

3. To have a study team member access my mental health service records, education records, juvenile justice records, department of social services and child protection records, or records from other service providers from which I've received services in the 12-months prior to the study and during the course of the study period and the costs of those services.

Yes
No

Youth's Name (Type or Print Full Name):	
Signature of Youth:	Date://
I,(Caregiver/Guardian)	, have read the above. My child may participate.
Guardian's Signature:	Date://

Thank you very much for your help in this important study. The information you give us will help us enhance services for children and families.

## EDUCATION SECTOR AND COMPARISON STUDY INFORMED CONSENT—YOUNG ADULT VERSION

## Purpose

The Center for Mental Health Services (CMHS), a center in the Substance Abuse and Mental Health Services Administration, an agency within the United States Department of Health and Human Services, is studying system of care programs. These programs are funded throughout the country to improve services for children and families. CMHS wants to know more about these services and how well they work. In order to assess the outcomes of these programs, ICF Macro is conducting a Sector and Comparison Study. You were invited to participate in this study because you were eligible to receive educational, mental health, substance use, or other behavioral services. We would like to know if you would agree to take part in the study we are doing. In this study, we are interested in finding out about how you feel; what you do at home, in school, and in the neighborhood; the kinds of services you have received; and how you feel about these services. The results of the study will be used to help improve the quality of services for children and families.

## **Description of Participation**

We may interview you up to five times. We will interview you at the beginning of the study. Then you will be contacted for additional interviews every 6 months for up to 24 months after that. We will ask you to continue to participate in the study even if you are no longer receiving services. The interviews will be conducted in your home or any other place that is best for you. Each interview will take about 1 hour.

You will be asked questions about your behavior at home, in school, and in the community. We will also ask you questions about your family and your experiences with the services you have received, including mental health and substance use services.

## **Administrative Records**

As part of the study, we would like your permission to make use of your school records, including disciplinary, attendance, and transfers, and other records related to services you may have received (for example, juvenile court records, records from the department of human services and child protection, mental health services records). Your agreement to participate in this study and your signature on this form provide your permission for the release of any of these records. We may also want to ask questions of agency representatives from juvenile court, the department of human services and child protection, and/or your school.

As part of the study, we will also be interviewing your teacher when enrollment into the study begins and every 6 months for up to 24 months and a school administrator at your school when enrollment begins and every 12 months for up to 24 months.

## **Risks and Benefits**

You will not get any benefits from being in this study. A risk is that you may feel uncomfortable about answering questions about yourself.

## Compensation

You will receive \$20 for each interview, and a \$50 bonus at the end of the 24-month period if you complete all 5 waves of data collection, to thank you for your time.

## **Protection of Information**

The study team has taken steps to protect your privacy. The information obtained in your interviews and your record review will be used for this study. Only authorized people will have access to the information. None of the interview or record review forms that are used in the study have your name on them. They only have special codes. Papers with your name on them will be kept in a locked filing cabinet. In reports, your answers will be grouped with those of others. We will never mention your name. The information obtained in your interviews will be released to the national evaluation team, consisting of ICF Macro, and our funding agency, the Substance Abuse and Mental Health Services Administration.

The study team has applied for a Confidentiality Certificate from the Federal government to protect the people who interview you from being forced, even under a court order or subpoena, to identify you. The Confidentiality Certificate does not imply that the government has approved or disapproved of this study. In addition, the Federal agency funding this research may see your information if it audits us to ensure that the study team protects your rights and safety.

There are two instances when the study team will not be able to keep your information confidential. If a study team member finds out that you plan to harm yourself or someone else or if there is alleged or suspected child abuse or neglect, we may report it to local authorities.

## **Rights Regarding Decision to Participate**

It is completely up to you whether you participate in the study. If you agree to take part in this study, you can change your mind and quit at any time. If you change your mind and quit, any information you gave to the study will be destroyed, if this is what you want. If you decide not to be in this study, it will not affect services for you or your. You should also know that if you decide to participate now and later change your mind, you can withdraw from the study at any time.

## **Contact Information**

If you have any questions about this evaluation study, you can call (*Research Coordinator*) to have your questions answered. You can call him/her collect at (555) 555–5555. To Contact the Institutional Review Board that reviewed this study, call 1-877-556-2218.

## **Voluntary Consent**

I have read this form or, it has been read to me, and I understand what it says. My questions have been answered. A copy of this form will be given to me.

By signing my name below, I freely agree to the following as indicated by a check in the YES box.

1. To be interviewed at the beginning of the study and every 6 months thereafter, for up to 24 months.

Yes
No

- 2. To have a study team member contact my school teacher and a school administrator to be interviewed for the study.
  - Yes
    No
- 3. To have a study team member access my mental health service records, education records, juvenile justice records, department of social services and child protection records, or records from other service providers from which I've received services in the 12-months prior to the study and during the course of the study period and the costs of those services.



Young Adult's Name (Type or Print Full Name): \_\_\_\_\_

Signature of Young Adult: \_\_\_\_\_

Date: \_\_/\_\_/\_\_\_

Thank you very much for your help in this important study. The information you give us will help us enhance services for children and families.

# JUVENILE JUSTICE SECTOR AND COMPARISON STUDY INFORMED ASSENT—YOUTH VERSION

## Purpose

The Center for Mental Health Services (CMHS), a center in the Substance Abuse and Mental Health Services Administration, an agency within the United States Department of Health and Human Services, is studying system of care programs. wants to know more about educational, mental health, substance use, and other behavioral services provided to children and their families. They want to know how well these services work. ICF Macro and EMSTAR Research, a local evaluator in Georgia, are working together on a study to learn more about how to make these services better by talking to children and families in the (**agency name/system name**).

The person who takes care of you is being asked questions for this study, and may have also answered questions in the past. Because you are 11 years old, we would like to ask you questions. You will be able to tell us about yourself and what you think about your services.

## **Description of Participation**

You will have an interview every 6 months. You may have up to five interviews. We can talk with you in your home or any other place that is best for you. Each interview will take about 1 hour.

You will be asked questions about how you feel. You will be asked about what you do at home, in school, and in your neighborhood. You will be asked about what you do with your family and friends. You will be asked about the services you have had. We will still ask to talk to you if you stop getting services.

We would like you to let us look at your records. These records include your grades, how much you were absent, and if you were ever in detention. We may also want to look at records about your services from other agencies where you may have received services. We will also want to talk to people who work for the Department of Juvenile Justice or the Juvenile Court.

## **Risks and Benefits**

You will not get any benefits from being in this study. You may learn new things about yourself. As a result of this study, services for youth, like the ones you receive, may get better. A risk is that you may feel uncomfortable about answering questions about yourself. We have taken steps to protect your privacy.

## Compensation

You will receive \$20 for each interview, and a \$50 bonus at the end of the 24-month period if you complete all 5 waves of data collection, to thank you for your time.

## **Protection of Information**

The study team has taken steps to protect your privacy. The information obtained in your interviews and your record review will be used for this study. Only authorized people will have access to the information. None of the interview or record review forms that are used in the study have your name on them. They only have special codes. Papers with your name on them will be kept in a locked filing cabinet. In reports, your answers will be grouped with those of others. We will never mention your name. The information obtained in your interviews will be released to the national evaluation team, consisting of ICF Macro, and our funding agency, the Substance Abuse and Mental Health Services Administration, and EMSTAR Research (local system of care evaluator).

There are two instances when the study team will not be able to keep your information confidential. If a study team member finds out that you plan to harm yourself or someone else or if there is alleged or suspected child abuse or neglect, we may report it to local authorities.

Also, we have applied for a Confidentiality Certificate from the Federal government to protect the people who interview you from being forced, even under a court order or subpoena, to identify you. The Confidentiality Certificate does not imply that the government has approved or disapproved of this study. In addition, the Federal agency funding this research may see your information if it audits us to ensure that the study team protects your rights and safety.

## **Rights Regarding Decision to Participate**

It is completely up to you whether you participate in the study. If you agree to take part in this study, you can change your mind and quit at any time. If you change your mind and quit, any information you gave to the study will be destroyed, if this is what you want. If you decide not to be in this study, it will not affect services for you or your family. You should also know that if you decide to participate now and later change your mind, you can withdraw from the study at any time.

## **Contact Information**

If you have any questions about this evaluation study, you can call (*Research Coordinator*) to have your questions answered. You can call him/her collect at (555) 555–5555. To contact the Institutional Review Board that reviewed this study you can call 1-877-556-2218.

## **Voluntary Assent**

I have read this form or, it has been read to me, and I understand what it says. My questions have been answered. A copy of this form will be given to me. By signing my name below, I freely agree to the following as indicated by a check in the YES box.

1. To be interviewed at the beginning of the study and every 6 months thereafter, for up to 24 months.

Yes
No

- 2. To have a study team member contact my court representative.
  - \_\_\_\_Yes

🗌 No

3. To have a study team member access my mental health service records, education records, juvenile justice records, department of social services and child protection records, or records from other service providers from which I've received services in the 12-months prior to the study and during the course of the study period and the costs of those services.

Yes
No

Youth's Name (Type or Print Full Name):	
Signature of Youth:	Date://
I,(Caregiver/Guardian)	, have read the above. My child may participate.
Guardian's Signature:	Date://

Thank you very much for your help in this important study. The information you give us will help us enhance services for children and families.

# JUVENILE JUSTICE SECTOR AND COMPARISON STUDY INFORMED CONSENT—YOUNG ADULT VERSION

## Purpose

The Center for Mental Health Services (CMHS), a center in the Substance Abuse and Mental Health Services Administration, an agency within the United States Department of Health and Human Services, is studying system of care programs. These programs are funded throughout the country to improve services for children and families. CMHS wants to know more about these services and how well they work. In order to assess the outcomes of these programs, ICF Macro is conducting a Sector and Comparison Study in collaboration with EMSTAR Research, a local evaluator in Georgia. You were invited to participate in this study because you were eligible to receive educational, mental health, substance use, or other behavioral services. We would like to know if you would agree to take part in the study we are doing. In this study, we are interested in finding out about how you feel; what you do at home, in school, and in the neighborhood; the kinds of services you have received; and how you feel about these services. The results of the study will be used to help improve the quality of services for children and families.

## **Description of Participation**

We may interview you up to five times. We will interview you at the beginning of the study. Then you will be contacted for additional interviews every 6 months for up to 24 months after that. We will ask you to continue to participate in the study even if you are no longer receiving services. The interviews will be conducted in your home or any other place that is best for you. Each interview will take about 1 hour.

You will be asked questions about your behavior at home, in school, and in the community. We will also ask you questions about your family and your experiences with the services you have received, including mental health and substance use services.

#### **Administrative Records**

As part of the study, we would like your permission to make use of your school records, including disciplinary, attendance, and transfers, and other records related to services you may have received (for example, juvenile court records, records from the department of human services and child protection, mental health services records). Your agreement to participate in this study and your signature on this form provide your permission for the release of any of these records. We may also want to ask questions of agency representatives from juvenile court, the department of human services and child protection, and/or your school.

We will also be interviewing a juvenile court representative, who could be your probation officer, case worker, or other juvenile court personnel most closely associated with your involvement with the juvenile justice system, when enrollment begins and every 6 months for up to 24 months.

## **Risks and Benefits**

You will not get any benefits from being in this study. A risk is that you may feel uncomfortable about answering questions about yourself.

## Compensation

You will receive \$20 for each interview, and a \$50 bonus at the end of the 24-month period if you complete all 5 waves of data collection, to thank you for your time.

## **Protection of Information**

The study team has taken steps to protect your privacy. The information obtained in your interviews and your record review will be used for this study. Only authorized people will have access to the information. None of the interview or record review forms that are used in the study have your name on them. They only have special codes. Papers with your name on them will be kept in a locked filing cabinet. In reports, your answers will be grouped with those of others. We will never mention your name. The information obtained in your interviews will be released to the national evaluation team, consisting of ICF Macro, our funding agency, the Substance Abuse and Mental Health Services Administration, and EMSTAR Research (local system of care evaluator).

The study team has applied for a Confidentiality Certificate from the Federal government to protect the people who interview you from being forced, even under a court order or subpoena, to identify you. The Confidentiality Certificate does not imply that the government has approved or disapproved of this study. In addition, the Federal agency funding this research may see your information if it audits us to ensure that the study team protects your rights and safety.

There are two instances when the study team will not be able to keep your information confidential. If a study team member finds out that you plan to harm yourself or someone else or if there is alleged or suspected child abuse or neglect, we may report it to local authorities.

## **Rights Regarding Decision to Participate**

It is completely up to you whether you participate in the study. If you agree to take part in this study, you can change your mind and quit at any time. If you change your mind and quit, any information you gave to the study will be destroyed, if this is what you want. If you decide not to be in this study, it will not affect services for you or your family. You should also know that if you decide to participate now and later change your mind, you can withdraw from the study at any time.

## **Contact Information**

If you have any questions about this evaluation study, you can call (*Research Coordinator*) to have your questions answered. You can call him/her collect at (555) 555–5555. To contact the Institutional Review Board that reviewed this study call 1-877-556-2218.

## **Voluntary Consent**

I have read this form or, it has been read to me, and I understand what it says. My questions have been answered. A copy of this form will be given to me.

By signing my name below, I freely agree to the following as indicated by a check in the YES box.

- 1. To be interviewed at the beginning of the study and every 6 months thereafter, for up to 24 months.
  - Yes No
- 2. To have a study team member contact my court representative.
  - Yes No
- 3. To have a study team member access my mental health service records, education records, juvenile justice records, department of social services and child protection records, or records from other service providers from which I've received services in the 12-months prior to the study and during the course of the study period and the costs of those services.

Yes No

Young Adult's Name (Type or Print Full Name): \_\_\_\_\_

Signature of Young Adult:	

Date: \_\_/\_\_/

Thank you very much for your help in this important study. The information you give us will help us enhance services for children and families.

Attachment G: Consent Letters for Longitudinal Child and Family Outcome Study and Service Experience Study

# SAMPLE INFORMED ASSENT—YOUTH VERSION

(Suggested Content and Wording)

Key Components of a Consent Form

#### Elements to Include:

## Purpose of the Study

- Funding source
- · Local system of care name
- Description of why the study will be conducted

**Description of Participation** 

- Participant responsibilities
- Description of data collection methods: interviews--frequency, duration; record review; observation, etc.
- Other guidelines (e.g., possible data sources, age, changes in participation over time, etc.)

#### **Risks and Benefits**

- Potential risk factors associated with participation
- Potential benefits that may be gained through participation

**Compensation for Participation** 

 Type and amount of compensation participant will receive for participation

#### **Contact Information**

 Contact information for someone working on the study who will be available to answer participant questions

#### Purpose

The **(system of care name)** in your community provides services to children and families. The Center for Mental Health Services, within the Substance Abuse and Mental Health Services Administration of the Federal government wants to know more about these services. They want to know how well these services work. The National Evaluation Team is talking to children and families in the **(system of care name)** to learn more about how to make these services better.

The person who takes care of you has been asked questions for this project in the past. Because you are now 11 years old, we would like to ask you questions. You will be able to tell us about yourself and what you think about the services you have received.

### **Description of Participation**

You will have an interview every 6 months. You may have up to five interviews. You may have fewer interviews, depending upon when you started services. We can talk with you in your home or any other place that is best for you. Each interview will take about 1 hour.

You will be asked questions about how you feel. You will be asked about what you do at home, in school, and in your neighborhood. You will be asked about what you do with your family and friends. You will be asked about the services you have had. We will still ask to talk to you if you stop getting services.

We would like you to let us look at your school records. These records include your grades, how much you were absent, and if you were ever in detention. We want to look at court records and records about your services. We may also want to talk to people who work for the court or your school.

## **Risks and Benefits**

You will not get any benefits from being in this project. A risk is that you may feel uncomfortable about answering questions about yourself.

## Compensation

You will receive \$XX for each interview to thank you for your time.

## **Contact Information**

If you have any questions about this evaluation project, you can call *(evaluator)* to have your questions answered. You can call him/her collect at (555) 555-5555. To contact the Institutional Review Board that reviewed this project, call (555) 555-5555.

Continued on next page

#### Key Components of a Consent Form

#### Protection of Information

- Protocol for maintaining participant
   privacy
- Mandated reporting requirements
- Description and purpose of the Federal Certificate of Confidentiality

#### **Rights Regarding Decision to Participate**

- Statement of participant rights to terminate participation at will
- Statement that the termination of participation will not lead to adverse consequences

Voluntary Assent

- Statement of participant understanding of the assent form
- Statement that participant has had all of his or her questions answered
- Permission to be interviewed
- Permission to access service provider records for 12 months previous to service and 24 months after the first service
- Signature line for participant to sign, thus assenting to participate
- Signature line for guardian signature
- Date

## **Protection of Information**

Anything we learn about you will be kept as secret as possible. We have taken steps to protect your privacy. None of the information for this study will have your name on it. It will have only special codes. Papers with your name on them will be kept in a locked filing cabinet. In reports, your information will be grouped together with information from others. We will never mention your name. Only approved people will be able to see your information. The information will be shared with the agency that pays for this study, companies that work for them, and other places that provide services to you.

There are some times when we cannot promise to keep your name secret. If you tell the person who interviews you that you plan to hurt yourself or someone else, then she/he [will/may] have to tell a doctor or some other authority so that you can get help. Interviewers must obey State laws and report certain kinds of diseases that other people can catch. And they must report child abuse.

Also, we have applied for a Certificate of Confidentiality from the Federal government to protect the people who interview you from being forced, even under a court order or subpoena, to identify you. An exception to privacy is if we learn about child abuse or neglect or if you tell the person who interviews you that you plan to harm yourself or someone else, then he/she will tell a doctor or some other authority so that you can get help. Interviewers may report child abuse. In addition, the

Federal agency funding this research may see your information if it audits us. The Certificate of Confidentiality does not imply that the government has approved or disapproved of this project.

## **Rights Regarding Decision to Participate**

I understand that I will not be in trouble if I do not want to be in the study or if I decide to quit later. I do not have to answer questions that I do not want to answer. If I change my mind and quit, all of my answers to questions will be destroyed, if that is what I want. No one will say that I can't be in other projects because I don't want to be in this project. No one can say that I cannot get services because I don't want to be in this project.

#### **Voluntary Assent**

I read this form, or it has been read to me, and I understand what it says. My questions (if any) have been answered. A copy of this form will be given to me. By signing my name below, I freely agree:

to be interviewed every 6 months, for up to 24 months		
<ul> <li>to have the project access my mental health records, education records, juvenile justice records, department of social services and child protection records, or service records from other services coordinated through (system of care name)</li> </ul>		Next 24 Months
Youth's Name (Type or Print Full Name):		
Signature of Youth:	Date:/	/
I,, have read the ab (Caregiver/Guardian)	ove. My child may	participate.
Guardian's Signature:	Date:/	/

## SAMPLE INFORMED CONSENT—YOUNG ADULT VERSION (Suggested Content and Wording)

#### Components of a Consent Form

#### Elements to include:

## Purpose of the Study

- Funding source
- Local program name
- Description of why the study will be conducted

**Description of Participation** 

- Participant responsibilities
- Description of data collection methods: interviews--frequency, duration; record review; observation, etc.
- Other guidelines (e.g., possible data sources, age, changes in participation over time, etc.)

#### **Risks and Benefits**

- Potential risk factors associated with participation
- Potential benefits that may be gained through participation

#### **Compensation for Participation**

 Type and amount of compensation participant will receive for participation

#### **Contact Information**

 Contact information for someone working on the study who will be available to answer participant questions

#### Purpose

The Center for Mental Health Services in the United States Department of Health and Human Services is sponsoring a national evaluation of programs that are funded by the Substance Abuse and Mental Health Services Administration to improve community-based mental health services for children and families. You were invited to participate in this project because you received such services. At that time, your family agreed to participate in the project we are doing. Now that you are 18 and a legal adult, we need to ask you again if you would like to continue participation in the project. In this project, we are interested in finding out about how you feel; what you do at home, in school, and in the neighborhood; the kinds of services you have received; and how you feel about these services. The results of the project will be used to help improve the quality of services for children and families. The national evaluation is authorized by Section 565 of the Public Health Service Act.

### **Description of Participation**

We will interview you up to five times depending upon whether you entered the study at the beginning or toward the end. Participation includes follow-up interviews every 6 months while you are in the evaluation. We will ask you to continue to participate in the project even if you do not receive services any longer. The interviews will be conducted in your home or any other place that is convenient for you. Each visit will take about 1 hour.

You will be asked questions about your behavior at home, in school, and in the community. We will also ask you questions about your family and your experiences with the services you have received, including mental health and substance use services.

As part of the project, we would like your permission to make use of your school records, including disciplinary, attendance, and transfers, and other records related to services you may have received (for example, juvenile court records, records from the department of human services and child protection, mental health services records). Your agreement to participate in this project and your signature on this form provide your permission for the release of any of these records. We may also want to ask questions of agency representatives from

juvenile court, the department of human services and child protection, and/or your school.

#### **Risks and Benefits**

You will not get any benefits from being in this project. A risk is that you may feel uncomfortable about answering questions about yourself.

#### Compensation

You will receive \$XX for each interview to thank you for your time.

#### **Contact Information**

If you have any questions about this evaluation project, you can call *(evaluator)* to have your questions answered. You can call him/her collect at (555) 555-5555. To contact the Institutional Review Board that reviewed this project, call (555) 555-5555.

#### Continued on next page

#### Components of a Consent Form

#### Protection of Information

- Protocol for maintaining participant
   privacy
- Mandated reporting requirements
- Description and purpose of the Federal Certificate of Confidentiality

#### **Rights Regarding Decision to Participate**

- Statement of participant rights to terminate participation at will
- Statement that the termination of participation will not lead to adverse consequences

#### Voluntary Consent

- Statement of participant understanding of the consent form
- Statement that participant has had all of his or her questions answered
- Permission to be interviewed
- Permission to access service provider records for 12 months previous to service and 24 months after the first service
- Signature line for participant to sign, thus assenting to participate
- Signature line for guardian signature
- Date

### **Protection of Information**

Anything we learn about you will be kept as secret as possible. We have taken steps to protect your privacy. None of the information for this study will have your name on it. It will have only special codes. Papers with your name on them will be kept in a locked filing cabinet. In reports, your information will be grouped together with information from others. We will never mention your name. Only approved people will be able to see your information. The information will be shared with the agency that pays for this study, companies that work for them, and other places that provide services to you.

There are some times when we cannot promise to keep your name secret. If you tell the person who interviews you that you plan to hurt yourself or someone else, then she/he [may/will] have to tell a doctor or some other authority so that you can get help. Interviewers must obey State laws and report certain kinds of diseases that other people can catch. And they must report child abuse.

Also, we have applied for a Certificate of Confidentiality from the Federal government to protect the people who interview you from being forced, even under a court order or subpoena, to identify you. An exception to privacy is if we learn about child abuse or neglect or if you tell the person who interviews you that you plan to harm yourself or someone else, then he/she will tell a doctor or some other authority so that you can get help. Interviewers may report child abuse. In addition, the Federal agency funding this research may see your information if it audits us. The Certificate of Confidentiality does not imply that the government has approved or disapproved of this project.

#### **Rights Regarding Decision to Participate**

I understand that I will not be in trouble if I do not want to be in the study or if I decide to quit later. I do not have to answer questions that I do not want to answer. If I change my mind and quit, all of my answers to questions will be destroyed, if that is what I want. No one will say that I can't be in other projects because I don't want to be in this project. No one can say that I cannot get services because I don't want to be in this project.

#### Voluntary Consent

I read this form or it has been read to me. I understand what it says. My questions (if any) have been answered. A copy of this form will be given to me. By signing my name below, I freely agree:

to be interviewed every 6 months, for up to 24 months	 
<ul> <li>to have the project access my mental health records, education records, juvenile justice records, department of social services and child protection records, or service records from other services coordinated through (system of care name)</li> </ul>	 <u>Next 24 Months</u>
Young Adult's Name (Type or Print Full Name):	 
Signature of Young Adult:	
Date://	