Caregiver—Other

Attachment B: System of Care Assessment

Family Stipend Receipt

Date: ____________________________________

Project: CMHS, #633430.0.008.0x.005

Location: ____________________________________

I, _______________________________________, received $25.00 for my participation in an
(print name)

interview for the national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program.

____
(signature)

System/Program___________________________ Interviewer___________________

Interviewed_______________________________ Assessment #_________________

INFORMED CONSENT
System of Care Assessment
Caregiver

The Center for Mental Health Services in the United States Department of Health and Human Services is sponsoring a national evaluation of children's mental health services and systems of care. You are invited to participate in this evaluation because your community has received funding to improve community-based mental health services for children and families. Your input is important to helping us understand how systems of care serve children and what works best. We are asking you to participate in a 90-minute interview with a trained interviewer who will ask you to respond to a set of questions about the children's mental health system of care in your community. These same questions are asked of all caregivers who have agreed to participate in this evaluation. Here are some things we want you to know about participating in the interview:

- Participation in the interview is completely voluntary.
- You may choose to discontinue the interview at any time, for any reason.
- Your name will not be used in any reports about this interview and no quotes will be attributed to you.
- There will be no direct benefit to you from this participating in the evaluation. The risk may be the discomfort some people feel when expressing their opinions or talking about their experiences. The services your child and family receive will not be impacted in any way by anything said during the interview.
- You will be given $25 in appreciation for your participation in the evaluation.
- A report that combines what we learn from all of the interviews conducted in your community will be sent to the children's mental health services program director and other program partners. They may share that report with others at their discretion.
- To help keep information about you confidential, we have obtained a Certificate of Confidentiality from the U.S. Department of Health and Human Services (DHHS). This Certificate adds special protection for the research information about you. This Certificate does not imply that the Secretary, DHHS, approves or disapproves of the project. The Certificate of Confidentiality will protect the investigators from being forced, even under a court order or subpoena, to release information that could identify you. We may release identifying information in some circumstances, however. For example, we may disclose medical information in cases of medical necessity, or take steps (including notifying authorities) to protect you or someone else from serious harm, including child abuse/neglect. Also, because this research is sponsored by DHHS, staff from DHHS may review records that identify you during an audit.
- Any questions you have about this interview will be answered before the interview begins.
- Any questions you may have after interview is concluded may be directed to Mary Spooner at ICF, Atlanta, GA. Her toll-free telephone number is 1-866-368-5657.
- Your signature below indicates that you understand the above and agree to participate.

Participant Printed Name ____

Participant Signature ____

Witness____ **Date** ___________________

2 signed forms: 1 for the interview participant and 1 for the interviewer

System/Program___________________________ Interviewer___________________

Interviewed_______________________________ Assessment #_________________

INFORMED CONSENT
System of Care Assessment
Parent/Guardian Approval for Youth Participant Aged 14–17

The Center for Mental Health Services in the United States Department of Health and Human Services is sponsoring a national evaluation of children's mental health services and systems of care. We are asking your permission to invite your child to participate in a 45-minute interview with a trained interviewer who will ask a set of questions about youth involvement in systems of care. Specifically, the purpose of the interview is to find out the different ways in which youth are involved in their system of care. For example, youth may be involved in planning their own services or making decisions about things that may affect other youth. Your child was identified as a potential participant because he/she currently receives services in a system of care community. If you allow us to invite your child to participate, here are some things you should know:

- Your child's participation is completely his/her choice. Even if you grant us consent, s/he may choose to not participate.
- Your child's name will not be used in any reports from this interview and no quotes will be attributed to your child. The information provided will be carefully protected and will not be shared with anyone, including parents or guardians.
- To help keep information about your child confidential, we have obtained a Certificate of Confidentiality from the U.S. Department of Health and Human Services (DHHS). This Certificate adds special protection for the research information about your child. This Certificate does not imply that the Secretary, DHHS, approves or disapproves of the project. The Certificate of Confidentiality will protect the investigators from being forced, even under a court order or subpoena, to release information that could identify your child. We may release identifying information in some circumstances, however. For example, we may disclose medical information in cases of medical necessity, or take steps (including notifying authorities) to protect your child or someone else from serious harm, including child abuse/neglect. Also, because this research is sponsored by DHHS, staff from DHHS may review records that identify your child during an audit.
- Your child may stop the interview at any time and for any reason or choose to not answer a question, without penalty or loss of benefits.
- Your child will receive $15 in appreciation for his/her participation.
- Other than the payment, there will be no direct benefit to your child from participating in this interview. Some youth may feel uncomfortable when expressing their opinions or talking about their experiences. Your child's participation and anything said in the interview will not affect the services your child and family receive any way.
- Any questions you or your child may have about this interview will be answered before the interview begins. If you have questions after the interview, you may contact Mary Spooner at ICF, Atlanta, GA. Her toll-free telephone number is 1-866-368-5657.

Voluntary Consent

I have read the above, or it has been read to me. My child may participate.

Parent/Guardian Printed Name ____

Parent/Guardian Signature ____

Witness____ **Date**_______________

System/Program__________________________ Assessment Date_________________

INFORMED CONSENT for RECORD REVIEW
System of Care Assessment

The Center for Mental Health Services in the United States Department of Health and Human Services is sponsoring a national evaluation of children's mental health services and systems of care. You are invited to participate in this evaluation because your community has received funding to improve community-based mental health services for children and families. Your input is important to helping us understand how systems of care serve children and what works best. We are asking for your permission to review the case record of services provided to you and your child through this program. We review the case records for the purpose of learning about how the program is developing and in determining the program's adherence to system of care principles. We review case records in all programs across the nation for the same purpose. Here are some things we want you to know about participating in the national evaluation:

- Participation is completely voluntary.
- No identifying information about your child or family is obtained from or recorded in notes taken on the case record review.
- Your name will not be used in any reports resulting from the national evaluation
- There will be no direct benefit to you from this participating in the record review or national evaluation. The services your child and family receive will not be impacted in any way.
- A report that combines what we learn from all of the information gathered from the system of care program in which you and your child participate will be sent to the children's mental health services program director and other program partners. They may share that report with others at their discretion.
- To help keep information about you confidential, we have obtained a Certificate of Confidentiality from the U.S. Department of Health and Human Services (DHHS). This Certificate adds special protection for the research information about you. This Certificate does not imply that the Secretary, DHHS, approves or disapproves of the project. The Certificate of Confidentiality will protect the investigators from being forced, even under a court order or subpoena, to release information that could identify you. We may release identifying information in some circumstances, however. For example, we may disclose medical information in cases of medical necessity, or take steps (including notifying authorities) to protect you or someone else from serious harm, including child abuse/neglect. Also, because this research is sponsored by DHHS, staff from DHHS may review records that identify you during an audit.
- Any questions you have about the record review or evaluation will be answered before the case record is reviewed.
- Any questions you have about the record review or national evaluation may be directed to Mary Spooner at ICF, Atlanta, GA. Her toll-free telephone number is 1-866-368-5657.
- Your signature below indicates that you understand the above and agree to participate in the national evaluation.

Participant Printed Name ____

Participant Signature ____

Witness____**Date**_____________________

2 signed forms: 1 for the interview participant and 1 for the interviewer

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

SAMPLE INFORMED CONSENT—CAREGIVER

(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.**
- **Description of youth involvement**
- **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**
- **Process or schedule for payment**

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 studying systems of care. These systems of care are funded to improve services for children and families. The ***(system of care name)*** where your child has received services is a part of this project. This project will be used to help make services for children and families better.

Description of Participation

As a part of this project, you will be interviewed up to five times. We will talk with you as services begin. Then you will be contacted every 6 months for up to 24 months after services began. You will be interviewed even if you and your child no longer receive services from ***(system of care name)***. We will talk with you at home, or at any other place that is best for you. In the interviews, you will be asked about your child, your family, and the services you have received. This will take about 2 hours.

As part of the project, we would also like to make use of your child's school and other records. These would include disciplinary, attendance, and transfer records. They may also include juvenile court records, records from the department of human services and child protection, and mental health services records related to your child's care. We may also want to ask questions of agency representatives from juvenile court, the department of human services and child protection, and/or your child's school.

If your child reaches age 11 at any time during this project, we will ask your child if we can interview him or her. At that time, we will ask for your permission to talk to your child. We will also describe the interview process to your child.

Risks and Benefits

There are no direct benefits to you being a part of this project. You may benefit from the services you receive. You may also learn new things about yourself. As a result of this project, services for children with mental health needs may get better. You may feel uncomfortable when talking about personal matters. We have taken steps to protect your privacy.

Compensation

If you agree to take part in this project, you will receive $XX for your first interview. You will be paid $XX for each interview at 6, 12, 18, and 24 months. Payment is made for the time you give to be interviewed.

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**
- **Description and purpose of the Federal Certificate of Confidentiality**
- **Mandated reporting requirements**

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 granting consent to participate**
- **Date**

Protection of Information

All information we learn about you will be protected. We have taken steps to protect your privacy. None of the information for this study will include your name or other information that identifies you. It only will include special codes. Any 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.

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. 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 if I agree to take part in this project, I can change my mind and quit at any time. If I change my mind and quit, any information I gave to the project will be destroyed, if this is what I want. If I decide not to be in this project, it will not affect services for my child and family. It also will not affect services that we might want in the future.

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 be interviewed every 6 months, for up to 24 months ____

- to have the project access my child's 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)***

	Past 12 Months	**Next 24 Months**
	____	____

Caregiver/Guardian (Type or Print Full Name): ____

Signature of Caregiver/Guardian:

____

Date: ___/___/____

Name of Child/Youth (Print) _____________________________________

Date: ___/___/____