

Caregiver—Other

Attachment B: System of Care Assessment

Family Stipend Receipt

Date: _____

Project: CMHS #633430.0.00x.00.001

Location: _____

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

interview for the national evaluation of the Comprehensive Community 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 face-to-face 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 the evaluation will be answered before the interview begins.
- Any questions you may have after the community visit is concluded may be directed to Freda Brashears at ICF Macro, 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** _____

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 face-to-face 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 and the study will be answered before the interview begins. If you have questions after the interview, you may contact Freda Brashears at ICF Macro, 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** _____

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 Freda Brashears at ICF Macro, 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** _____

Attachment E: Sector and Comparison Study

Script to Introduce the Education and Juvenile Justice Sector and Comparison Studies

“The Center for Mental Health Services (CMHS), a center of the Substance Abuse and Mental Health Services Administration, is funding an evaluation of educational, mental health, substance use, and other behavioral health services provided to children and their families. Funds have also been provided to conduct an evaluation of the services children and families receive. Their goal is to improve services in the future and to make it easier for children and families to receive the care they need. We would like to talk to you about the study to see if your family might want to take part.

“First, you need to know that whether you participate in this study is completely up to you. If you decide not to participate, your child’s and family’s services will not be affected in any way. You should also know that if you decide to participate now and later change your mind, you can withdraw from the evaluation at any time.

“If you decide to participate, you will be asked some questions about your child and family, and about the services you have received. We will want to ask you these questions now and every 6 months for up to 2 years. The maximum number of times we would interview you would be five times in a 2-year period. Each interview will take between 1 hour and 15 minutes and 1 hour and 45 minutes. If your child is 11 years old or older, we would like to ask him/her some questions in a separate interview. That interview will take about an hour. You and your child will be paid for each interview and will receive a bonus for completing all interviews.

“We know that some of the information you would be giving us might be private and personal. Be assured that all the information you share will be kept strictly private.

“When would be a good time for someone to talk to you about participating in the study?

“Would that also be a good time to do the first interview with you and your child (if applicable)?”

Script to Introduce the Child Welfare Sector and Comparison Study

“The Center for Mental Health Services (CMHS), a center of the Substance Abuse and Mental Health Services Administration, is funding an evaluation of educational, mental health, substance use, and other behavioral health services provided to children and their families. Funds have also been provided to conduct an evaluation of the services children and families receive. Their goal is to improve services in the future and to make it easier for children and families to receive the care they need. We would like to talk to you about the study to see if your family might want to take part.

“First, you need to know that whether you participate in this study is completely up to you. If you decide not to participate, your child’s and family’s services will not be affected in any way. You should also know that if you decide to participate now and later change your mind, you can withdraw from the evaluation at any time.

“If you decide to participate, you will be asked some questions about your child and family, and about the services you have received. We will want to ask you these questions now and every 6 months for up to 2 years. The maximum number of times we would interview you would be five times in a 2-year period. Each interview will take between 1 hour and 15 minutes and 1 hour and 45 minutes. You will be paid for each interview and will receive a bonus for completing all interviews.

“We know that some of the information you would be giving us might be private and personal. Be assured that all the information you share will be kept strictly private.

“When would be a good time for someone to talk to you about participating in the study?

“Would that also be a good time to do the first interview with you?”

EDUCATION SECTOR AND COMPARISON STUDY

CONSENT TO CONTACT

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 mental health 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. The study team is talking to families involved in mental health services from funded system of care communities, and to families involved in mental health services in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your child's behavior and functioning, the kinds of services you and your child receive, and how you feel about these services. The (*agency name*) is a part of this study. We would like your permission to contact you to tell you more about the study.

Contact for Further Information

Whether you decide to have someone contact you about participating in this study is completely up to you. If you decide not to be contacted, your child's and family's services will not be affected in any way. 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.

Protection of Information

Any information from this study will be kept private. Special precautions will be taken to protect your and your child's privacy. The forms in the study will be coded so that they cannot be associated with individual names. The information that is collected will be used only in reports in which individual names are never used or in which individuals are never identified.

I understand that my signature below indicates that I have read the Consent to Contact Form or it has been read to me. By signing my full name below, I understand a member of the project staff will review my child's current service records and that I might be contacted, using the information that I provide, to receive a complete description of the study and an invitation to participate. I understand that my child may not be eligible to participate depending on whether or not they meet study eligibility criteria.

(parent/caregiver initials)

Contact Information

Referring Clinician/Provider: _____

First

Last

Phone Number: _____

E-mail: _____

Name of Child's School District: _____

(Please include the full name of the school district. Please do not abbreviate.)

Name of Child's School: _____

(Please include the full name of the school. Please do not abbreviate.)

Name of School Program: _____

(eg. School-based program, Day Treatment Program, or other specialized educational program the child is attending)

Caregiver's Name: _____

First

Last

Child's Name: _____

First

Last

Caregiver's Address: _____

Caregiver's Telephone Number(s): Home: _____

Work: _____

Cell: _____

E-mail: _____

Caregiver's Primary Language: English

Non-English

(Identify): _____

Child's Primary Language: English

Non-English

(Identify): _____

Signature of Caregiver: _____

Date: _____

Signature of Witness: _____

Date: _____

JUVENILE JUSTICE SECTOR AND COMPARISON STUDY

CONSENT TO CONTACT

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 mental health 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. The study team is talking to families involved with juvenile justice, who are receiving services from funded system of care communities, and to families involved with juvenile justice in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your child's behavior and functioning, the kinds of services you and your child receive, and how you feel about these services. The (*juvenile justice agency name*) is a part of this study. We would like your permission to contact you to tell you more about the study.

Contact for Further Information

Whether you decide to have someone contact you about participating in this study is completely up to you. If you decide not to be contacted, your child's and family's services will not be affected in any way. 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.

Protection of Information

Any information from this study will be kept private. Special precautions will be taken to protect your and your child's privacy. The forms in the study will be coded so that they cannot be associated with individual names. The information that is collected will be used only in reports in which individual names are never used or in which individuals are never identified.

I understand that my signature below indicates that I have read the Consent to Contact Form or it has been read to me. By signing my full name below, I understand a member of the project staff will review my child's current service records and that I might be contacted, using the information that I provide, to receive a complete description of the study and an invitation to participate. I understand that my child may not be eligible to participate depending on whether or not they meet study eligibility criteria.

(parent/caregiver initials)

CHILD WELFARE SECTOR AND COMPARISON STUDY

CONSENT TO CONTACT

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 mental health 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 and Walter R. McDonald & Associates, Inc. are conducting a Sector and Comparison Study. The study team is talking to families, involved with child welfare who are receiving services from funded system of care communities and to families involved with child welfare in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your child's behavior and functioning, the kinds of services you and your child receive, and how you feel about these services. The (*child welfare agency name*) is a part of this study. We would like your permission to contact you to tell you more about the study.

Contact for Further Information

Whether you decide to have someone contact you about participating in this study is completely up to you. If you decide not to be contacted, your child's and family's services will not be affected in any way. 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.

Protection of Information

Any information from this study will be kept private. Special precautions will be taken to protect your and your child's privacy. The forms in the study will be coded so that they cannot be associated with individual names. The information that is collected will be used only in reports in which individual names are never used or in which individuals are never identified.

I understand that my signature below indicates that I have read the Consent to Contact Form or it has been read to me. By signing my full name below, I understand that I will be contacted, using the information that I provide, to receive a complete description of the study and an invitation to participate. I understand that my child may not be eligible to participate in the study depending on whether or not they meet study eligibility criteria.

(parent/caregiver initials)

EDUCATION SECTOR AND COMPARISON STUDY

INFORMED CONSENT—CAREGIVER

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 mental health 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. The study team is talking to families receiving mental health services from funded system of care communities and to families in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your child's behavior and functioning, the kinds of services you and your child receive, and how you feel about these services. The (*agency/school name/system name*) where your child is involved is a part of this study.

Description of Interview Participation

As a part of this study, you may be interviewed up to five times. We will interview you at the beginning of the study. Then you will be contacted every 6 months for up to 24 months after that. Each interview will take about an hour and a half. You will be interviewed even if you and your child are no longer involved with (*agency name*). A member of the study team 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 about your services. We will also be interviewing your child's primary teacher when enrollment begins and every 6 months for up to 24 months and a school administrator at your child's school every year.

If your child reaches age 11 at any time during this study, 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.

Services and Cost Study

The study team would also like to review records from other agencies that have provided services to you and your child for a Services and Costs Study. The goal of the Services and Costs Study is to learn about the array of services that children and families receive and the costs for those services. The Services and Cost study also tries to understand the relationship among services, service costs, and outcomes for children and their families. The study will try to answer the following questions:

- a. What types of services are used by the families in the study?
- b. Do children who receive different types of services have different results?
- c. Which services have the best results for children and families?
- d. How much does it cost to offer effective services to children?

The records that the study team would review might come from Medicaid, mental health service providers, juvenile justice, schools, department of human services and child protection or other

service providers related to your child's care. The information the study team would obtain from these records is as follows:

- Child's birth date
- Dates he/she received services
- Description of services received
- Unit of service (hours, minutes, days, etc.)
- Charge and/or adjusted charge for service
- Location of service delivery

In order to get the administrative records on the services provided to you and your child and their costs, we will need to give identifying information to the organizations from which you have received services.

The study team member will review records from the 12 months prior to your participation in the study and will review records during the study period of 24 months. The information for the Services and Cost Study will be entered on the computer with your child's special code, so no connection can be made between the services and your child.

Risks and Benefits

There are no risks or benefits associated with participating in the study. However, some of the questions may make you feel uncomfortable because they ask about personal matters. You may skip questions you would rather not answer. The study team hopes that you may feel good knowing that the information you provide will help to improve services for families with children and youth with behavioral or emotional difficulties in the future. We have taken steps to protect your privacy.

Compensation

If you agree to take part in this study, you will receive \$40 for your first interview that you complete. You will be paid \$40 for each interview you complete at 6, 12, 18, and 24 months and a \$50 bonus at the end of the 24-month period if you complete all 5 interviews. You are paid in order to compensate you for the time you give for the interviews.

Protection of Information

The study team has taken steps to protect your privacy. The information obtained in your interview and your child's 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 this study will have your name on them. Your name and contact information will be kept separate under lock and key and only authorized members of the study team will have access to it. The information is saved on computers with high levels of security. When study results are reported, your answers are grouped with others and reported in summary form. Reports will never mention any information that could identify you or your child. In other words, it may be reported that "68% of families who have young child with behavioral or emotional difficulties feel very stressed." The information obtained in your interviews and your child's record review 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 your child and 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 child's school teacher and the school administrator to be interviewed for the study.
 Yes
 No
3. To have a study team member access my child's mental health service records, education records, juvenile justice records, department of social services and child protection records, or records from other service providers for which services were received in the 12-months prior to the study and during the course of the study period and the costs of those services.
 Yes

No

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

Signature of Caregiver/Guardian:

Date: ___/___/___

Name of Child/Youth (Print) _____

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—CAREGIVER

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 mental health 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. The study team is talking to families receiving services from funded system of care communities and to families in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your child's behavior and functioning, the kinds of services you and your child receive, and how you feel about these services. The (*juvenile justice agency name*) is part of this study.

Description of Participation

As a part of this study, you may be interviewed up to five times. We will interview you at the beginning of the study. Then you will be contacted every 6 months for up to 24 months after that. Each interview will take about an hour and a half. You will be interviewed even if you and your child are no longer involved with (*agency name*). A member of the study team 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 about your services. We will also be interviewing a juvenile court representative, who could be the youth's probation officer, case worker, or other juvenile court personnel most closely associated with the youth's involvement with the juvenile justice system, when enrollment begins and every 6 months for up to 24 months.

If your child reaches age 11 at any time during this study, 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.

Services and Costs Study

The study team would also like to review records from other agencies that have provided services to you and your child for a Services and Costs Study. The goal of the Services and Costs Study is to learn about the array of services that children and families receive and the costs for those services. The Services and Cost study also tries to understand the relationship among services, service costs, and outcomes for children and their families. The study will try to answer the following questions:

- e. What types of services are used by the families in the study?
- f. Do children who receive different types of services have different results?
- g. Which services have the best results for children and families?
- h. How much does it cost to offer effective services to children?

The records that the study team would review might come from Medicaid, mental health service providers, juvenile justice, schools, department of human services and child protection or other service providers related to your child's care. The information the study team would obtain from these records is as follows:

- Child's birth date
- Dates he/she received services
- Description of services received
- Unit of service (hours, minutes, days, etc.)
- Charge and/or adjusted charge for service
- Location of service delivery

In order to get the administrative records on the services provided to you and your child and their costs, we will need to give identifying information to the organizations from which you have received services.

The study team member will review records from the 12 months prior to your participation in the study and will review records during the study period of 24 months. The information for the Services and Cost Study will be entered on the computer with your child's special code, so no connection can be made between the services and your child.

Risks and Benefits

There are no risks or benefits associated with participating in the study. However, some of the questions may make you feel uncomfortable because they ask about personal matters. You may skip questions you would rather not answer. The study team hopes that you may feel good knowing that the information you provide will help to improve services for families with children and youth with behavioral or emotional difficulties in the future. We have taken steps to protect your privacy.

Compensation

If you agree to take part in this study, you will receive \$40 for your first interview that you complete. You will be paid \$40 for each interview you complete at 6, 12, 18, and 24 months and a \$50 bonus at the end of the 24-month period if you complete all 5 interviews. You are paid in order to compensate you for the time you give for the interviews.

Protection of Information

The study team has taken steps to protect your privacy. The information obtained in your interview and your child's 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 this study will have your name on them. Your name and contact information will be kept separate under lock and key and only authorized members of the study team will have access to it. The information is saved on computers with high levels of security. When study results are reported, your answers are grouped with others and reported in summary form. Reports will never mention any information that could identify you or your child. In other words, it may be reported that "68% of families who have young child with behavioral or emotional difficulties feel very

stressed.” The information obtained in your interviews and your child’s record review 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 your child and 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 child’s court representative.
 Yes
 No
3. To have a study team member access my child’s mental health service records, education records, juvenile justice records, department of social services and child protection records, or records from other service providers for which services were received in the 12-months prior to the study and during the course of the study period and the costs of

those services. By signing below, you agree to have the above described record information released from your provider agencies to ICF Macro (the Federal-level system of care evaluator), and EMSTAR Research (local system of care evaluator).

- Yes
- No

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

Signature of Caregiver/Guardian:

_____ Date: ___/___/___

Name of Child/Youth (Print) _____ 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.

CHILD WELFARE SECTOR AND COMPARISON STUDY

INFORMED CONSENT—CAREGIVER SCREENING INTERVIEW

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 mental health 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 and Walter R. McDonald & Associates, Inc. are conducting a Sector and Comparison Study. The study team is talking to families involved with child welfare who are receiving services from funded system of care communities and to families involved with child welfare in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your child's behavior and functioning, the kinds of services you and your child receive, and how you feel about these services. The (*child welfare agency name*) is part of this study.

Description of Interview Participation

As part of the study, a member of the study team will interview you within the next week to determine whether your child is eligible for the study. The interview will take about 25 minutes. A member of the study team will talk with you at home, or at any other place that is best for you. In the interview, you will be asked about your child's behavior.

If your child is determined to be eligible for the study, you will be invited to participate in the study. You will be contacted shortly after this interview, if your child is eligible for the study.

Risks and Benefits

There are no risks or benefits associated with participating in the screening interview. However, some of the questions may make you feel uncomfortable because they ask about personal matters. You may skip questions you would rather not answer. The study team hopes that you understand that these questions will help us determine whether your child is eligible for the study.

Compensation

If you agree to take part in the screening interview, you will receive \$20 for your participation. You are paid in order to compensate you for the time you give for the interview.

Protection of Information

The study team has taken steps to protect your privacy. The information obtained in your interview will be used for this study. Only authorized people will have access to the information. None of the interview forms that are used in the screening interview will have your name on them. Your name and contact information will be kept separate under lock and key and only authorized members of the study team will have access to it. The information is saved on computers with high levels of security. If your child is enrolled in the study, information obtained from the screening interview will be used as part of the study. Reports will never

mention any information that could identify you or your child. The information obtained in your interview will be released to the national evaluation team, consisting of Walter R. McDonald & Associates, Inc. and 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 screening interview. If you agree to take part in this interview, 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 participate in the screening interview, it will not affect services for your child and family.

If after the screening interview it is determined that your child is eligible for the study, you will be contacted about participating in the study. A separate consent for participating in this study will be required.

Contact Information

If you have any questions about this 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 be interviewed and provide information about my child to see if he or she is eligible for the study.

Caregiver/Guardian (Type or Print Full Name):

Signature of Caregiver/Guardian:

Date: ___/___/___

Name of Child/Youth (Print) _____ Date: ___/___/___

Thank you very much for agreeing to participate in the screening interview. The information you provide us will help determine whether your child is eligible for the study.

CHILD WELFARE SECTOR AND COMPARISON STUDY

INFORMED CONSENT—FOSTER PARENT SCREENING

INTERVIEW

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 mental health 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 and Walter R. McDonald & Associates, Inc. are conducting a Sector and Comparison Study. The study team is talking to families involved with child welfare who are receiving services from funded system of care communities and to families involved with child welfare in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your foster child's behavior and functioning, the kinds of services you and your foster child receive, and how you feel about these services. The (*child welfare agency name*) is part of this study.

Description of Interview Participation

As part of the study, a member of the study team will interview you within the next week to determine whether the child is eligible for the study. The interview will take about 25 minutes. A member of the study team will talk with you at home, or at any other place that is best for you. In the interview, you will be asked about the child's behavior.

If the child is determined to be eligible for the study, you will be invited to participate in the study. You will be contacted shortly after this interview, if the child is eligible for the study.

Risks and Benefits

There are no risks or benefits associated with participating in the screening interview. However, some of the questions may make you feel uncomfortable because they ask about personal matters. You may skip questions you would rather not answer. The study team hopes that you understand that these questions will help us determine whether the child is eligible for the study.

Compensation

If you agree to take part in the screening interview, you will receive \$20 for your participation. You are paid in order to compensate you for the time you give for the interview.

Protection of Information

The study team has taken steps to protect your privacy. The information obtained in your interview will be used for this study. Only authorized people will have access to the information. None of the interview forms that are used in the screening interview will have your name on them. Your name and contact information will be kept separate under lock and key and only authorized members of the study team will have access to it. The information is saved on computers with high levels of security. If the child is enrolled in the study, information obtained

from the screening interview will be used as part of the study. Reports will never mention any information that could identify you or the child. The information obtained in your interview will be released to the national evaluation team, consisting of Walter R. McDonald & Associates, Inc. and 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 screening interview. If you agree to take part in this interview, 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 participate in the screening interview, it will not affect services for the child and your family.

If after the screening interview it is determined that the child is eligible for the study, you will be contacted in the near future about participating in this study. A separate consent for participating in the study will be required.

Contact Information

If you have any questions about this 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 be interviewed and provide information about the child to see if he or she is eligible for the study.

Foster Parent (Type or Print Full Name):

Signature of Foster Parent:

Date: ___/___/___

Name of Child/Youth (Print) _____ Date: ___/___/___

Thank you very much for your participation in the screening interview. The information you provide us will help determine whether the child is eligible for the study.

CHILD WELFARE SECTOR AND COMPARISON STUDY

INFORMED CONSENT—CAREGIVER

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 mental health 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 and Walter R. McDonald & Associates, Inc. are conducting a Sector and Comparison Study. The study team is talking to families who are receiving services from funded system of care communities and to families involved in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your child's behavior and functioning, the kinds of services you and your child receive, and how you feel about these services. The (*child welfare agency name*) is part of this study.

Description of Interview Participation

As part of the study, a member of the study team will interview you within the next month and possibly every 6 months for up to 2 years. The maximum number of times you will be interviewed is five times in a 2-year period. Each interview will take about an hour and a half. You will be interviewed even if you and your child are no longer involved with (*child welfare agency name*). A member of the study team 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 any services you have received.

Child Welfare Record Review

As part of the study, a member of the study team, with your permission, will review your child's child welfare record. The purpose of this review is to identify services received, child and family background, and information about child welfare goals.

Services and Cost Study

The study team would also like to review records from other agencies that have provided services to you and your child for a Services and Costs Study. The goal of the Services and Costs Study is to learn about the array of services that children and families receive and the costs for those services. The Services and Cost study also tries to understand the relationship among services, service costs, and outcomes for children and their families. The study will try to answer the following questions:

- i. What types of services are used by the families in the study?
- j. Do children who receive different types of services have different results?
- k. Which services have the best results for children and families?
- l. How much does it cost to offer effective services to children?

The records that the study team would review might come from Medicaid, mental health service providers, Head Start, or early intervention service providers. The information the study team would obtain from these records is as follows:

- Child's birth date
- Dates he/she received services
- Description of services received
- Unit of service (hours, minutes, days, etc.)
- Charge and/or adjusted charge for service
- Location of service delivery

In order to get the administrative records on the services provided to you and your child and their costs, we will need to give identifying information to the organizations from which you have received services. The study team member will review records from the 12 months prior to your participation in the study and will review records during the study period of 24 months. The information for the Services and Cost Study will be entered on the computer with your child's special code, so no connection can be made between the services and your child.

Risks and Benefits

There are no risks or benefits associated with participating in the study. However, some of the questions may make you feel uncomfortable because they ask about personal matters. You may skip questions you would rather not answer. The study team hopes that you may feel good knowing that the information you provide will help to improve services for families with young children with behavioral or emotional difficulties in the future. We have taken steps to protect your privacy.

Compensation

If you agree to take part in this study, you will receive \$40 for your first interview that you complete. You will be paid \$40 for each interview you complete at 6, 12, 18, and 24 months and a \$50 bonus at the end of the 24-month period if you complete all 5 interviews. You are paid in order to compensate you for the time you give for the interviews.

Protection of Information

The study team has taken steps to protect your privacy. The information obtained in your interviews and your child's 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 will have your name on them. Your name and contact information will be kept separate under lock and key and only authorized members of the study team will have access to it. The information is saved on computers with high levels of security. When study results are reported, your answers are grouped with others and reported in summary form. Reports will never mention any information that could identify you or your child. In other words, it may be reported that "68% of families who have young child with behavioral or emotional difficulties feel very stressed." The information obtained in your interviews and your child's record review will be released to the national evaluation team, consisting of Walter R. McDonald & Associates, Inc. and 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 your child and 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 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 within the next month and every 6 months thereafter, for up to 24 months

Yes
 No

2. To have a study team member access my child's child welfare agency records reviewed now and every 6 months, for up to 24 months.

Yes
 No

3. To have a study team member access my child's service records, including records from Medicaid, Head Start, mental health, and early intervention services. The purpose of

accessing these records is to identify all services received in the 12-months prior to the study and during the course of the study period and the costs of those services.

- Yes
- No

Caregiver/Guardian (Type or Print Full Name):

Signature of Caregiver/Guardian:

Date: ___/___/___

Name of Child/Youth (Print) _____

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.

CHILD WELFARE SECTOR AND COMPARISON STUDY

INFORMED CONSENT—FOSTER PARENT

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 mental health 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 and Walter R. McDonald & Associates, Inc. are conducting a Sector and Comparison Study. The study team is talking to families involved with child welfare who are receiving services from funded system of care communities and to families involved with child welfare in communities not receiving funding to develop system of care services. In this study, we are interested in finding out about your foster child's behavior and functioning, the kinds of services you and your foster child receive, and how you feel about these services. The (*child welfare agency name*) is part of this study. We would like your permission to contact you to participate in the study.

Description of Interview Participation

As part of the study, a member of the study team will interview you within the next month and possibly every 6 months for up to 2 years. You will be interviewed up to 5 times in a 2-year period. Each interview will take about an hour and a half. A member of the study team will talk with you at home, or at any other place that is best for you. In the interviews, you will be asked about the child, your family, and any services you have received.

Risks and Benefits

There are no risks or benefits associated with participating in the study. However, some of the questions may make you feel uncomfortable because they ask about personal matters. You may skip questions you would rather not answer. The study team hopes that you may feel good knowing that the information you provide will help to improve services for families with young children with behavioral or emotional difficulties in the future.

Compensation

If you agree to take part in this study, you will receive \$40 for your first interview. You will be paid \$40 for each interview at 6, 12, 18, and 24 months after you complete each interview. You will also be provided a \$50 bonus at the end of the 24-month period if you complete all 5 interviews. You are paid in order to compensate you for the time you give for the interviews.

Protection of Information

The study team has taken steps to protect your privacy. The information obtained in your interviews will be used for this study. Only authorized people will have access to the information. None of the interview forms that are used in the study will have your name on them. Your name and contact information will be kept separate under lock and key and only authorized members of the study team will have access to it. The information is saved on computers with

high levels of security. When study results are reported, your answers are grouped with others and reported in summary form. Reports will never mention any information that could identify you or your foster child. In other words, it may be reported that “68% of families who have young child with behavioral or emotional difficulties feel very stressed.” The information obtained in your interviews will be released to the national evaluation team, consisting of Walter R. McDonald & Associates, Inc. and 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 the child and your family.

Contact Information

If you have any questions about this 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 be interviewed and provide information about the child within the next month and every 6 months thereafter, for up to 24 months.

Foster Parent (Type or Print Full Name):

Signature of Foster Parent:

Date: ___/___/___

Name of Child/Youth (Print) _____

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 CONSENT—CAREGIVER 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.
- 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 by the Substance Abuse and Mental Health Services Administration 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 [may/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: ___/___/___