

Approved by the Human Subjects Committee University of Kansas, Lawrence Campus (HSCL) on 8/2/12. Approval expires one year from 11/1/2011 HSCL # 19572
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INFORMED CONSENT STATEMENT – Declined KIPP Services, Data Collection Only

Kansas Intensive Permanency Project

INTRODUCTION

The School of Social Welfare at the University of Kansas protects human subjects participating in research. This information is provided to help you decide if you wish to participate in this study. You can decide not to sign this form and not to participate in this study. Even if you agree to participate, you are free to withdraw from the study at any time. If you do withdraw, it will not affect your relationship with the University of Kansas or any other participating agency, including your foster care agency.

PURPOSE OF THE STUDY

The University of Kansas School of Social Welfare, Implementation Sciences International, Inc. (ISII), the State of Kansas, and the state's four private foster care agencies (KVC Behavioral Healthcare, TFI Family Services, St. Francis Community Services, and Youthville) are conducting a research project on the impact of parent management training on family reunification. The goal of the study is to determine whether in-home, intensive services provided to parents helps children with behavioral or emotional challenges to reunify faster and to stay home after reunification.

This local study is a part of the Permanency Innovations Initiative, a national initiative that seeks to build the evidence for new interventions that will improve permanency outcomes for groups of children and youth. The overall evaluation of this initiative is being led by Westat and subcontractors James Bell & Associates (JBA), the School of Social Work of the University of North Carolina at Chapel Hill (UNC), Andrew Barclay Associates (ABA), and Ronna Cook Associates (RCA).

PROCEDURES

You have been asked to participate in the study of parent management training and family reunification because you are the parent of a child with emotional or behavioral challenges. This study used a lottery to determine which services families get, which means that you may have been included in either a parent management training group or in an assessment group. This was determined by chance. Both groups will continue to receive the usual foster care case management services that are provided by the foster care agency. As part of the KIPP study, information will be collected by a KIPP Data Liaison, about you, your family, and your child(ren) at your home or in a private room of the foster care agency.

The KIPP Data Liaison will collect information from you at three points: 1) soon after your child(ren) are taken into custody; 2) at approximately six months; and 3) 12 months after your child(ren) enter foster care. The Data Liaison will make an effort to collect the information during one visit, at three different points in time. The total time for each visit is expected to be about 1 to 2 hours.

The following are the main pieces of information that will be collected for the KIPP project:

- 1) The KIPP Data Liaison will complete a KIPP Caregiver Initial Info sheet with you. This will just take about five minutes and will ask basic questions about your age, living situation, education, etc.
- 2) The KIPP Data Liaison may interview you about your child and family soon after your child(ren) enter care. The first interview could take about 30-45 minutes. Interviews after this initial interview (at 6 and 12 months), if necessary, will take approximately 30-45 minutes. Information from the interview will be used by the KIPP Data Liaison to complete the “North Carolina Family Assessment Scale” (NCFAS). This is required for all families participating in KIPP. It will give us information about how your family is doing and what challenges you are experiencing.
- 3) The KIPP Data Liaison will ask you to complete a questionnaire called the “Social Skills Improvement System” (SSIS). It will take about 10 minutes each time to fill out. This questionnaire asks about your child(ren)—their strengths and difficulties.
- 4) Finally, you will be asked to do a “Family Interaction Task” (FIT). The FIT is a series of activities we ask you and one of your children to do together so we can watch to see what is easy for you as a family and what is harder. The FIT is video recorded so we can take notes about how your child is responding to you. It will take about 30 minutes. As part of the FIT, you will be asked to fill out some checklists. These take about 10-20 minutes to complete.

You may be contacted in the future for additional permission to use video recordings of you and your child for educational and/or research purposes. **You may decline at any time to release these video recordings.** Video recordings of you and your family would never be used without getting your permission first.

ALTERNATIVE PROCEDURES

If you choose to not participate in this project, you will be offered all the foster care case management services that are usually offered to families (e.g., case management, referral to community supports and services) and you will not be asked to complete all the assessments listed above for the purpose of the KIPP study.

RISKS

Discussing sensitive issues and being observed can evoke many feelings. The KIPP Data Liaison or your case manager can address these feelings as they arise. We do not anticipate any direct risks from participating in this study. We do not anticipate any risk to your child(ren) from participating in this study, other than normal discomfort from talking about sensitive topics. If you disclose information that you might harm yourself or another person, the KIPP Data Liaison will report this information to your case manager and treatment team.

BENEFITS

You may benefit from this study because you will receive extra check-ins from a trained provider. These check-ins may help you to focus on what you want to happen with your family. Also, your participation in this study may help other families. The information gathered may be used, for example:

- 1) to help families move toward reunification faster;
- 2) to improve the quality of treatment families receive;
- 3) to bring advanced training to therapists who work with children and families;

- 4) to improve quality of services delivered to families with children like yours; and
- 5) to develop prevention and treatment strategies.

PAYMENT TO PARTICIPANTS

Participants will receive a gift card for each evaluation assessment they participate in up to a maximum of 3 assessments. After each of the assessment meetings, participants will receive one \$10 gift card per caregiver unit and one \$10 gift card per focal child/youth for a total of \$20 per family. The project researchers may ask for your and your child's social security numbers in order to comply with federal and state tax and accounting regulations.

PARTICIPANT CONFIDENTIALITY

To help protect your privacy, the research team has obtained a Certificate of Confidentiality from the United States Department of Health and Human Services (DHHS). With this Certificate, we cannot be forced to share information that may identify you in any court or legal proceeding, even under a court order or subpoena. The researchers will use the Certificate to resist any demands for information that would identify you or your child, with a few exceptions. We will in all cases, take the necessary action, including reporting to authorities, to prevent serious harm to yourself or others. This includes the reporting of suspected child abuse or neglect. We are also required to share your information upon request of DHHS for the purpose of audit or evaluation.

To further protect your privacy, all information will be coded so that it cannot be associated with any individual's name or other identifying information. A master sheet that lists the names of individuals with their respective code numbers will be kept in a locked file at the University of Kansas School of Social Welfare research office and can be accessed only under the strict supervision of the local project principal investigators. Original documents, except for the NCFAS, will be shredded at the time of data entry into an electronic database. The NCFAS will be maintained by the agency that recorded the information. All electronic data and video recordings will be maintained by KU on a password-protected secure server. All access to individual records or video recordings, now or after you and your child(ren) leave the study, will occur under close supervision of the local project principal investigators, in compliance with the statutes of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which stipulates that research findings must be held for six years following the granting of consent.

The information gathered will be used only for research, scientific, or educational purposes.

CONFIDENTIALITY AND PUBLISHING

As results become available, members of the research team will publish the results in academic journals and present the results at regional and national conferences. All results published and/or presented will be in aggregate or summary form. That is to say, results of the study will look at patterns and averages of information gathered from all of the subjects, rather than looking at specific examples. No identifiable information about you or your participation in this project will be used in future publications or presentations.

PRIVACY ACT

Your privacy will be protected, under the Privacy Act of 1974 (Public Law 93-579), to the fullest extent possible. We will not include information that identifies you or your family in any reports.

QUESTIONS ABOUT PARTICIPATION

During the course of your participation in the KIPP project, you may have questions about data collection or the treatment procedures. The Data Liaison may be able to answer your questions, or you may speak with the KIPP Supervisor at the foster care agency, or the principal investigators, who are listed at the end of this consent form. If you would feel more comfortable discussing your concerns about the project with someone outside the project staff, you are free to call the Coordinator of the Human Subjects Committee, The University of Kansas Lawrence Campus at (785) 864-7429.

VOLUNTARY PARTICIPATION AND RIGHT TO WITHDRAW

Your participation in this study is voluntary. You have the right to refuse to answer any question(s). Some questions might be personal or sensitive. These questions are important to the project, and we would like you to answer them honestly. However, if there are some questions you do not want to answer, you may skip them and move on to other questions. You also have the right not to do certain parts of the project. Your refusal to participate in this study will involve no penalty or loss of benefits to which you are otherwise entitled. You remain eligible to receive treatment as usual. You may end participation in the project, including the stopping of video recording, at any time without penalty or loss of benefits to which you are otherwise entitled. You have the right to withdraw from this project at any time and also can require that the video recordings that include you and your family be erased or destroyed.

I have received written information about how to request that my video recordings be destroyed.

FOLLOW-UP STUDY

The research team may want to do a follow-up study in the future to see how the families who participated with us are doing. Your participation in the follow-up study would be completely voluntary and we would ask your consent at that time.

In regard to future outcome follow-up studies:

_____ I consent to be contacted in the future to participate in an outcomes follow-up study.

_____ I DO NOT consent to be contacted in the future to participate in an outcomes follow-up study

REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from your foster care agency or the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

PARTICIPANT CERTIFICATION

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429 or (785) 864-7385 or write the Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7568.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

SIGNATURE

My signature below indicates my voluntary agreement to participate in this study. By signing this consent, I am stating that I am legally authorized to consent for my child's participation.

Participant's Signature (Parent/Caregiver)

Participant's Signature (Parent/Caregiver)

Print Name

Print Name

Date

Date

Date of IRB approval of this consent: November 1, 2011, HSCL #19572

Expiration date of IRB approval of this consent: November 1, 2012

OMB No: FORTHCOMING

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