Consent and Parental Permission Document

STUDY SUMMARY

You and your child are being asked to take part in a research study. Participation in this study is voluntary.

Many of the youth who have contact with the juvenile justice system will go on to be resilient and lead productive lives. But some youth will return to detention—what explains the different outcomes for these youth? Researchers at the University of Utah are conducting a research study to begin to answer this question called the ***Adolescents Coping with Experiences Study (ACES)***, which has been funded by the National Institute of Justice. The purpose of this study is to test theories about how the kinds of stress youth experience in their lives, and how youth's emotional, cognitive, and interpersonal styles of coping with stress, might help us understand why some youth will return to detention and others will not over the course of the next four years.

We would like your child to complete surveys and we will measure their natural body responses. We will ask you to complete surveys about your child's behavior. He full explanation of what we are asking you and your child to do is described below in this consent document in the "Study Procedure" section.

Risks of participating are small. However, it is possible that you or your child may feel upset thinking about or talking about stressful life experiences or behaviors. These risks are similar to those experienced when discussing personal information with others. If you or your child feels upset from this experience, you/your child can tell the researcher, and he/she will tell you about resources available to help.

There are no direct benefits for taking part in this study. We hope the information we get from this study may help us learn how to keep youth from re-entering detention centers in the future.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you would like to participate in this study and whether you will allow your child to take part in this study.

STUDY PROCEDURE

1. **What will <u>your child</u> be asked to do?** Each youth who agrees to participate will be asked to complete a survey about their thoughts, behaviors, and relationships as well as stressful life experiences once per year over the next four years. Youth will be asked to answer questions such as, "I watch out for danger or things I am afraid of," "I have trouble concentrating or paying attention," "I express my feelings openly," and "I try to avoid getting too close to people."

   Researchers also will take some measurements of your child's natural body responses. One of these responses is called Electrodermal Responding (EDR), which will measure sweat on the

Commented [AS1]: Informed consent should begin with a **concise and focused presentation of the key information** that is most likely to facilitate understanding of the reasons why one may or may not want to participate in research.

In general, the beginning of an informed consent would include a concise explanation of the following: 1) The fact that consent is being sought for research, and participation is voluntary; 2) Purpose of the research, expected duration, and procedures; 3) Reasonably foreseeable risks; 4) Benefits that may be reasonably expected; 5) Appropriate alternative procedures or courses of treatment, if any.

Elements included in a concise summary need not be repeated. For example, if all the benefits are explained in the concise summary, it does not need to be repeated later to satisfy the required elements of informed consent.

Commented [AS2]: In some cases, parents as well as their children are asked to participate in research. Investigators may combine a consent document with parental permission as long as it is clear throughout the document that both consent and parental permission is being sought. The language throughout the document should refer to both the parent and child.

Commented [AS3]: Is there a statement that the study involves research? Yes.

Commented [AS4]: Is there an explanation of the purposes of the research? Yes.

Commented [AS5]: Is the expected duration of participation stated? Yes.

Commented [AS6]: A summary of the study procedures is included in the concise summary. The full procedures will be explained in the body of the consent.

Commented [AS7]: Is there a description of any foreseeable risks or discomforts to the participant? Yes.

Commented [AS8]: Is there a description of any benefits to the participants or others? Yes.

Commented [AS9]: Is there a description of the procedures to be followed including the identification of any procedures that are experimental? Yes.

palm of your child's hand, and the other is called Respiratory Sinus Arrhythmia (RSA), which is a measure of heart rate. We will measure these responses by having your child attach sensors (sticky pads) to his/her body while he or she watches a short clip from the PG-rated movie *The Champ* and also while s/he describes life events of their choice. There will be no pain or discomfort during the testing and these procedures are not in any way physical harmful. Because this testing is not part of a clinical assessment, you or your child will not get any feedback on the results of the testing. In order to help us to correctly record your child's responses, this part of the study will be audiotaped. The audiotapes will be stored in password-protected electronic files that only the researchers can access, and will be destroyed at the end of the study.

It will take approximately two hours to gather all information from your child, but this will be broken up into two sessions completed while your child is at the detention center, or in your home if your child is in the community. We will contact your child again once a year for the next four years and will invite your child to participate in the same study again so we can understand how things might change over time.

If your child turns 18 during this study, and becomes legally an adult, s/he will be given the chance to sign a consent form to say whether s/he wants to keep participating in the study.

2. **What will <u>you</u> be asked to do?** Each parent/guardian who agrees to participate will be asked to complete a survey about their youth's behavior and experiences that will take about 40 minutes. Parents will be asked to answer questions such as, "I am usually successful when I try to get my child to do or not do something," and "My child does not show emotions to others." If you and your child agree to participate in the study, we also will include information from the youth's detention records, including his or her legal history, any incidents during detention, Juvenile Justice intake and probation assessments, and legal charges that occur over the course of the next four years.

CONFIDENTIALITY

Another potential, but unlikely, risk is a breach of confidentiality. Many steps have been taken by the research team to make sure that the confidentiality of all data collected are protected. All study data will be stored on secure servers and password-protected hard drives. Any identifying information (e.g., names) will be removed from our records and replaced with a code. A list linking the code and your child's identifiable information will be kept separate from the research data in a locked file cabinet in a locked room at the university. All data collected will be identified only by that code (not by your child's name). As a result, no one outside of the research team will know what answers you or your child have given to any question. The fact that your child participated in the research will also be confidential. Forms including your name or your child's name (such as this one) will be kept in a locked file cabinet within a locked office, accessible only by the research team.

The information collected about you in this study will not be used for future research studies.

Commented [AS10]: Is there a statement describing the confidentiality of records? Yes.

Commented [AS11]: Is there a statement about the collection of identifiable private information or identifiable biospecimens? Yes. A statement that the participant's information collected as part of the research, even if identifiers are removed, will not be used or distributed for future research studies is included.

To help us further protect your privacy, this research also is protected by 42 USC 3789g, a federal confidentiality law that states no information you provide through your participation in this project can be disclosed to anyone without your consent. With this law, the researchers cannot be forced to disclose information that may identify you or your child, even by a court subpoena, in any federal, state, or local civil, criminal or other proceedings.

If you disclose information that gives study staff a reason to believe that a child or disabled or elderly adult has been subjected to abuse or neglect, study staff will report that information to Child Protective Services, Adult Protective Services, or the nearest law enforcement agency to the extent required by law.

Commented [AS12]: This statement should be used if the study involves the possibility of disclosure of abusive situations.

PERSON TO CONTACT

If you have questions, complaints or concerns about this study, you can contact <<PI Name>>, a Professor of Psychology at the University of Utah at <<phone number or e-mail>>. If you feel you or your child has been harmed as a result of participation, please call <<contact name and phone number>> who may be reached during the hours of 8:00 am to 5:00 pm, Monday through Friday.

Commented [AS13]: Is the necessary contact information provided? Yes.

Institutional Review Board: Contact the University of Utah Institutional Review Board (IRB) if you have questions regarding your child's rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Commented [AS14]: This statement is required for all studies. This language should be included verbatim.

Research Participant Advocate: You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

Commented [IRB15]: If the study is conducted at the University of Utah, include this statement.

VOLUNTARY PARTICIPATION

It is up to you to decide whether you would like to take part in this study, and whether you will allow your child to participate. There will be no penalty if you refuse to participate or decide to withdraw from this research. You are also free to skip any questions that you do not feel comfortable answering. This will not affect your or your child's relationship with the investigator. The decision about whether you or your child participates in this study will have no effect on the way your child is treated in the detention center and will have no effect on length of stay, what happens in court, or any other decisions related to your child's legal status. Even if you agree to take part, your child will be asked to agree as well and your child only will be enrolled in the study if he or she voluntarily agrees to do so.

Commented [AS16]: Is there a statement that participation is voluntary? Yes.

Commented [AS17]: Is there a statement that individuals may refuse to participate or discontinue participation without penalty or loss of benefits? Yes.

COSTS AND COMPENSATION TO PARTICIPANTS

Caregivers who complete the first session of the study will receive compensation in the form of a $10 gift card. Families who agree to participate in the follow-up sessions over the course of the next four years will receive compensation at the completion of each follow-up visit in the form of a gift card for youth and a cash honorarium for caregivers. In total families will receive $80 ($60 gift card for youth, $20 for caregiver) at Time 2, and $110 ($80 gift card for youth, $30 for caregiver) at Time 3. Should

Commented [AS18]: A description of compensation including the anticipated prorated payment is an additional element of informed consent. This is not generally required in studies that are no greater than minimal risk. However, since there is compensation offered, it is appropriate to include.

youth be in detention at the time of any of the follow-up visits, the gift cards will be held by staff and given to youth at the time they are released.

CONSENT

I confirm I have read the information in this consent and parental permission form and have had the opportunity to ask questions. I will be given a signed copy of this consent and parental permission form to keep.

PLEASE NOTE: Participation in this study requires BOTH signatures requested below. If you do not want to sign both places, you are free not to be in this study.

Consent to reporting

Commented [AS19]: A consent to reporting checkbox is not required by the IRB but there is no objection to the investigator using the extra checkbox.

☐ I agree that the researchers will make a report if they learn about actual or suspected abuse, neglect or exploitation of a child or disabled or elderly adult or that a child is in danger of hurting self or others.

_____
Printed Name

_____ _____
Sign your name on this line Date

☐ I voluntarily agree to participate, and I voluntarily allow my child to take part in this study.

☐ I voluntarily agree to participate, but I DO NOT want my child to take part in this study.

☐ I DO NOT want to participate, but I voluntarily allow my child to take part in this study.

_____
Child's Name

_____ _____
Parent/Caregiver/Guardian's Name Relationship to Child

_____ _____

Parent/Caregiver/Guardian's Signature Date

_____

Name of Person Obtaining Consent

_____ _____

Signature of Person Obtaining Consent Date

CONSENT FOR FOLLOW-UP CONTACT

I am willing to be contacted again in one year to be invited to participate in the next session of this four-year study. I understand that agreeing to be contacted does not mean that I promise to agree to participate at that time.

☐ I agree to allow the researchers to re-contact me in one year.

Home phone: _____ My cell phone: _____

My spouse/partner's cell phone: _____ Youth's cell phone: _____

Address: _____

_____

Phone number of a family member who will always know how to reach me: _____

Phone number of a friend who will always know how to reach me: _____

Email address: _____

May we privately message you on Facebook? __ yes __ no

Your Facebook url: _____

Are you on other social media sites where we can link up with you to send you private messages?

Instagram: _____

Kik: _____

Twitter: _____

Snapchat: _____

Others?: _____

Commented [AS20]: Investigators may request permission to contact individuals for future studies. It is important to state that giving consent to be contacted does not mean that the individual consents to participate in other research.