Consent Document for Participants Who Have Turned 18

STUDY SUMMARY

You 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 three years.

We would like you to complete surveys and we will measure your natural body responses. The full explanation of what we are asking you 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 caregiver 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 caregiver 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.

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 you be asked to do?** Each person 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 three years of this study. Individuals 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 natural body responses. One of these responses is called Electrodermal Responding (EDR), which will measure sweat on the palm of your hand, and the other is called Respiratory Sinus Arrhythmia (RSA), which is a measure of heart rate. We will measure these responses by having you attach sensors (sticky pads) to your body while you watch a short video clip from a PG-rated movie and also while you describe life events of your choice. There will be no pain or discomfort during the testing and these

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

Commented [AS3]: Is there an explanation of the purposes of the research? Yes.

Commented [AS4]: Is the expected duration of participation stated? Yes.

Commented [AS5]: 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 [AS6]: Is there a description of any foreseeable risks or discomforts to the participant? Yes.

Commented [AS7]: Is there a description of any benefits to the participants or others? Yes.

Commented [AS8]: Is there a description of the procedures to be followed including the identification of any procedures that are experimental? Yes.

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procedures are not in any way physical harmful. Because this testing is not part of a clinical assessment, you will not get any feedback on the results of the testing. In order to help us to correctly record your 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 you, but this will be broken up into two sessions completed while you are in your home. We will contact you again once a year until the three years of the study have been completed and will invite you and your caregiver to participate in the same study again so we can understand how things might change over time.

2. **What will <u>your caregiver</u> be asked to do?** Each parent/guardian who agrees to participate will be asked to complete a survey about your 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."

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 any 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 name). As a result, no one outside of the research team will know what answers you or your caregiver have given to any question. The fact that you participated in the research will also be confidential. Forms including your name or your caregiver's name (such as this one) will be kept in a locked file cabinet within a locked office, accessible only by the research team.

Commented [AS9]: Is there a statement describing the confidentiality of records? Yes.

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

Commented [AS10]: 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.

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 [AS11]: 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 <<phone number or e-mail>>. If you feel you have 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 [AS12]: 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

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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.

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.

VOLUNTARY PARTICIPATION

It is up to you to decide whether you would like to take part in this study. 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 caregiver's relationship with the investigator. The decision about whether you or your caregiver participates in this study will have no effect on the way you are treated, what happens in court, or any other decisions related to your legal status. Even if your caregiver agrees to take part, you will be enrolled in the study only if you voluntarily agree to do so.

COSTS AND COMPENSATION TO PARTICIPANTS

There are no costs or compensation related to participating to this first session of the study. Families who agree to participate in the follow-up sessions over the course of the next three 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.

CONSENT

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

☐ 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 in the study

Commented [AS13]: This statement is required for all studies. This language should be included verbatim.

Commented [IRB14]: If the study is conducted at the University of Utah, include this statement.

Commented [AS15]: Is there a statement that participation is voluntary? Yes.

Commented [AS16]: Is there a statement that individuals may refuse to participate or discontinue participation without penalty or loss of benefits? Yes.

Commented [AS17]: A description of costs is an additional element of informed consent. This information is not generally required in studies that are no greater than minimal risk.

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.

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.

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_____
Printed Name

_____ _____
Sign your name on this line Date

_____
Name of Person Obtaining Consent

_____ _____
Signature of Person Obtaining Consent Date

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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 three-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.

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