



Informed Consent for Participation in Research Activities

Childhood Trauma: Characteristics, Symptoms, and Treatment Outcomes

Principal Investigator: Joel Epstein, PhD PI's Phone Number: (314) 516-7340 PI's Email: epsteinj@umsl.edu
Co-Investigator: Jerry Dunn, PhD Co-I's Phone Number: (314) 516-7342 Co-I's Email: dunnjer@msx.umsl.edu

This document is designed to inform you about, and invite you to participate in the research we do at the Children's Advocacy Services of Greater St. Louis (CASGSL), a Center within the Department of Psychological Sciences at the University of Missouri – Saint Louis. In this document, we refer to “your child.” Depending on your particular situation, this may mean either a child you care for and/or a child for whom you have legal guardianship.

Our research study is about trauma characteristics, trauma symptoms, and treatment outcome among children and adolescents who have experienced traumatic events (e.g., physical or sexual abuse, witnessing an act of violence). We are asking for your participation because your child will be receiving services at CASGSL and we make efforts to conduct research on the services we provide.

All clients at CASGSL complete assessment measures both at the beginning of treatment and throughout the course of their therapy. We do this to help guide the course of treatment and track progress that is being made. Although all of our clients complete these assessments as part of their treatment, we are also asking for your permission to share these data with our research staff.

This form is designed to explain the reasons we are making this request. Please read it carefully and ask any questions you may have before agreeing to be in the research. Your participation in this research is voluntary. Your decision whether to participate will not affect current or future relations with CASGSL or the University of Missouri-St. Louis (UMSL) and will not affect the treatment services received at CASGSL. If you decide to participate, you are free to withdraw at any time without affecting the services you receive.

Why am I being asked to participate?

Due to their developmental level, children and adolescents are not always able to provide all important information related to their traumatic experiences. Because of your close relationship with your child, you have access to significant amounts of information related to his/her emotional and behavioral functioning. Therefore, you have also been asked to participate because you can provide important information regarding your child's traumatic experiences, trauma-related difficulties, and response to trauma-focused treatment that your child may not be able to provide.

What is the purpose of this research?

The purpose of this research is to learn more about how children are affected by traumatic experiences and the factors involved in recovery from those experiences. Results from this research study may be used to make recommendations about how to improve mental health services for children affected by traumatic experiences.

What procedures are involved?

- Both you and your child will be asked to complete several forms at the beginning of treatment, every three months during treatment, and at the end of treatment.
- You will complete most of the forms using a tablet computer (iPad). Some of the forms are paper and you will fill them out with a pen or pencil.
- The forms take about 1-2 hours to complete at the beginning of treatment, and about one hour to complete at later times.
- As mentioned above, both you and your child will complete these forms whether or not you decide to be a part of this study. Therapists use the answers on the forms to guide treatment.
- If you do participate in the study, we will remove all identifying information from the forms before they are analyzed. Caregiver responses will be coded with a unique and anonymous “family ID” so that they are associated with their children’s responses. Any research we publish will never personally identify anyone that is part of this study.

What are the potential risks and discomforts?

It is the standard clinical practice of CASGSL to collect this information as part of an intake assessment, which will aid your child’s therapist in developing a treatment plan, and periodically during the course of therapy to assess any emotional and/or behavior changes. It is possible that you and/or your child may experience some distress while completing the questionnaires, as you and your child will be talking about the impact of the traumatic experience. The therapists are trained mental health professionals, and will be available to help alleviate any distress. Another potential risk of this research is that our data security measures might be breached. We do, however, make efforts to minimize this possibility by storing all information on secure computers. Also, because your child will be discussing traumatic events that s/he may have experienced, we are mandated to report any suspected abuse, neglect, or risk of self-harm. Finally, you may experience some eye strain while completing the forms on the iPad.

Are there benefits to taking part in the research?

There are no direct benefits for participating in this study. The information you provide will be used to assess the quality of the treatment services we provide and to investigate other issues related to traumatic experiences among children.

What about privacy and confidentiality?

The only people who will know that you are a research subject are members of the research team. No information about you, or provided by you during the research will be disclosed to others without your written permission, except under the following conditions:

- a) A signed written authorization from a child’s legal guardian is required to release information pertaining to a minor child.
- b) Missouri State Law (#210.110, 2.14.140, 210.1650) requires all mental health professionals to report any and all cases of known or suspected child or elder abuse.
- c) To the extent permitted by law, we will report to involved parties, state mental health agencies, and/or law enforcement agencies situations in which we reasonably believe that a client is at risk of causing harm to him/herself or other persons.
- d) Information required or permitted to be disclosed by law (for example, R.S.Mo. 630.140 and related or similar laws and regulations as they may be from time to time enacted or amended) might not be regarded by the court as confidential. Also, information you authorize to be disclosed to third parties may not be regarded or treated by those persons as confidential.
- e) Periodically, charts are reviewed by funding sources performing program audits on our services. These reviewers are obligated to respect confidentiality procedures on any individual client data they review.

When the results of the research are published, or discussed in conferences, no information will be included that would reveal your identity. Any information that is obtained in connection with this study and that can be identified with you or your child (e.g., name, address, school name, place of employment, phone number, etc.) will remain confidential and will be disclosed only with your permission or as required by law. The only information that will be shared with other professionals outside of our research team will be the responses and scores from measures that you completed and non-identifying demographic information.

All private information will be kept on a computer server, protected by the University of Missouri’s secure network. Data will be entered in a database by a member of our research team. Your child will be identified by a research number, and

there will be no identifying information about you or your child in the database. The list of research participants and corresponding research numbers is kept in a separate password-protected database also contained on the secure computer. Only the research team has access to this list.

Will I be paid for my participation in this research?

You will not be paid for your participation in this study.

Can I withdraw or be removed from the study?

You can choose whether to be in this study. If you volunteer to be in this study, you may withdraw at any time without any consequences. You also may refuse to answer any questions and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so (for example, if you provide fraudulent answers or intentionally respond to the surveys in a deceptive manner). If you decide to end your participation in the study, please contact the investigator, Dr. Joel Epstein, via phone (314-516-7340) or email (epsteinj@umsl.edu).

Who should I contact if I have questions?

The researcher conducting this study is Dr. Joel Epstein (314-516-7340; epsteinj@umsl.edu). You may ask any questions you have now. If you have questions later, you may contact him at the phone number or email address listed above.

What are my rights as a research subject?

If you have any questions about your rights as a research subject, you may call the Chairperson of the Institutional Review Board at (314) 516-5897.

What if I am a UMSL student?

You may choose not to participate, or to stop your participation in this research, at any time. This decision will not affect your class standing or grades at UMSL. The investigator also may end your participation in the research, but not your ongoing treatment. If this happens, your class standing will not be affected. You will not be offered or receive any special consideration if you participate in this research.

What if I am a UMSL employee?

Your participation in this research is, in no way, part of your university duties, and your refusal to participate will not in any way affect your employment with the university or the benefits, privileges, or opportunities associated with your employment at UMSL. You will not be offered or receive any special consideration if you participate in this research.

Remember: Your decision regarding whether to participate in the research and follow-up survey is voluntary and will not in any way affect your child’s treatment. In addition, you have the right to revoke consent at any time during your child’s treatment and follow-up. If you choose not to participate in our research, the information will be only gathered for clinical purposes at intake, at 3-month intervals during therapy, and at the end of therapy and will not be included in our research analyses.

By signing below, you are agreeing to allow CASGSL to use the data described above for research purposes.

You may request a copy of this form for your records.

I have read the above statement and have been able to express my concerns, to which the investigator has responded satisfactorily. I believe I understand the purpose of the study, as well as the potential benefits and risks that are involved. I hereby give my informed and free consent for my child and myself to be a participant in this research.

Client’s Printed Name

Parent or Guardian’s Signature

Date

Parent or Guardian’s Printed Name

Witness' Signature

Date

Witness' Printed Name