311. Research Involving Foster Children/Youth In Child And Family Services Custody

**Major objectives:**

Child and Family Services will cooperate with bona fide research by providing information on or allowing recruitment of foster children/youth in the custody of Child and Family Services as long as the research is approved in accordance with the standards and procedures of the DHS Institutional Review Board, which may be found on their website at [http://www.hs.utah.gov/irb/index.htm](http://www.hs.utah.gov/irb/index.htm).

**Applicable Law**

- Utah Code Ann. §52-4-1 through 7, Open and Public Meetings.
- Utah Code Ann. §62A-3-302, Purpose of Adult Protective Services Program.

**Practice Guidelines**

A. When a researcher proposes a research study that involves children/youth in Child and Family Services custody, the following steps must be taken to grant informed consent prior to the researcher being given any confidential information or having contact with clients or their private data. Federal regulations define “research” as “a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.” This may include, but is not limited to, accessing individual client records, interviewing the child or others about the child, observing the child, or treating a child as part of the research study.

1. The Child and Family Services research representative to the DHS Institutional Review Board (DHS IRB) must review and approve the research. The Child and Family Services research representative will consult with the division director and/or region directors when the research impacts regional workload or is of greater than minimal risk. Risk level is determined by the DHS IRB or the research representative. Minimal risk means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. The review
will consist of evaluating whether or not the research is in the best interests of Child and Family Services and its clients (including the children), the researcher has made adequate provision for obtaining all required informed consents and informed assents, the research protocols and procedures are designed to ensure confidentiality, respect, and ethical treatment during the researcher’s gathering of the data, storage, retrieval of the data, and publication of the data, the research study involves no more than minimal risk to subjects or the direct benefits to the subjects outweigh the risks, the research methodology is sufficiently sound to yield results that offer a potential benefit to the Department or Child and Family Services, and the research protocol protects individual privacy rights and complies with the Department's Vision and Mission Statements, the Department Code of Ethics, and any applicable rules or statutes, including Utah Code Annotated §63-2-202(8). Approval will be documented on Child and Family Services Level Approval of Research Form (see Section 311 – Foster Children Research Involvement – Caseworker Consent Form).


3. Informed consent for children/youth in Child and Family Services custody (unless written consent has been waived by the DHS IRB):
   a. The Child and Family Services caseworker for the child/youth will consult with the foster parents (adoptive parents in research with adoptive children/youth) and may contact therapists, school personnel, and others who work closely with the child to determine if the child/youth will be available and ready to participate in the proposed research, and to consider if there are any concerns about the child/youth participating in the research. If it is decided that the child/youth can participate, the caseworker must sign the informed consent and document on the “Foster Children Research Involvement – Caseworker Consent Form” who they consulted prior to deciding to give consent.
b. If the research is greater than minimal risk and the child/youth is under 18 years of age and the goal of the child/youth is ‘Return Home’ or ‘Custody to Relative Guardian’ or if parental rights have not been terminated, the parents or relatives must be consulted and give their permission for the child to participate. If they give their permission they must also sign the informed consent form. If they do not give their consent the child/youth cannot participate in the research.

c. If the child/youth has the maturity to understand the implications of participating in research, they must be consulted about their potential participation. It must be explained that participation is voluntary, if they do not assent it will not in any way affect services they or their families receive from Child and Family Services, and if they do assent they can withdraw from the research project at any time without penalty. Evaluation of the child/youth’s level of maturity is done by the Child and Family Services caseworker after consultation with foster or adoptive parents and other appropriate collateral contacts (i.e. education representatives, a therapist, caretaker, etc.). If the child/youth (younger than 18 years of age) agrees to participate, he or she must sign an informed assent form. If the youth is 18 years or older they must sign the informed consent form. If the child/youth does not agree, they cannot participate in the research.

d. If the research is greater than minimal risk, the office of the Guardian ad Litem must be contacted. The Guardian ad Litem representing the child/youth must be given a description of the research project. If the Guardian ad Litem expresses concerns regarding the child/youth’s participation in the research, the child/youth cannot participate. The Guardian ad Litem may be contacted via phone or certified mail. They need to be provided the anticipated start date for the research. They also need to be provided a date by which response is required so that they can express any concerns they have prior to then. The Guardian ad Litem must be given at least ten days to review and respond to the research proposal. Contact with the Guardian ad Litem must be documented for each child/youth.

e. Copies of consent forms, assent forms, and the “Foster Children Research Involvement – Caseworker Consent Form” will then be sent to the Child and Family Services research representative to be stored with the research proposal.
B. Once these steps have been completed and if proper consent and assent have been given, the Child and Family Services research representative may release information to the researcher or the caseworkers may allow participation of foster children/youth and the researcher may proceed with their research project.