

441—175.42 (235A) Person conducting research. The supervisor of the central abuse registry shall be responsible for determining whether a person requesting child abuse information is conducting bona fide research, whether the research will further the official duties and functions of the central abuse registry, and whether identified information is essential to the research design. A bona fide research design is one which shows evidence of a good-faith, academically objective and sincere intent to add to the body of knowledge about child abuse. To make this determination, the central abuse registry shall require the person to submit credentials and the research design. Additional criteria for approval of a research project may include whether the research involves contact with subjects of child abuse information, and whether contact with department personnel is required to complete the research design. If it is determined that the research will involve use of identified information, the central abuse registry shall also determine under what circumstances and in what format the information is to be used and shall execute an agreement with the researcher which will enable the researcher to obtain access to identified information on subjects of child abuse investigations, as an agent of the central abuse registry. The department will require the researcher to assume costs incurred by the department in obtaining or providing information for research purposes. The department shall keep a public record of persons conducting this research.

175.42(1) *Child abuse factors.* For purposes of conducting research pursuant to Iowa Code sections 235A.15 and 235A.23, official duties and functions of the central abuse registry shall include analysis or identification of child abuse factors in at least one of the following areas:

- a. Causes of abuse—victim, parent and perpetrator characteristics, types of abuse, and correlations to family and environmental factors.
- b. Effects of abuse—immediate and long-term effects of abuse on the individual child victim, the child's family and the perpetrator, in areas such as family functioning, foster placement, emotional and medical problems, and criminal activity; and effects of abuse on the community and society in general.
- c. Prevention of abuse—intervention, prevention and treatment strategies.
- d. Treatment of abuse—impact of service delivery upon recidivism and maintenance of the family unit.
- e. Reporting of abuse—mandatory and permissive reporter characteristics, training needs, and perception of the department's protective services to children and families.
- f. Identification of strengths and weaknesses in statute, policy or practice concerning child abuse services.

175.42(2) *Guidelines.* To be accepted by the central abuse registry, a research proposal originating outside the department shall meet the following guidelines:

- a. The proposal shall meet the criteria listed above as "official duties and functions" of the central abuse registry.
- b. The research shall be conducted by a competent researcher, evidenced by affiliation with a recognized human services agency, government body, or academic, social work or medical facility. The researcher shall demonstrate an ability to conduct nonbiased research and present findings in a professional and responsible manner which will benefit the department in providing protective services to children and families.
- c. The proposed research shall not unduly interfere with the ongoing duties and responsibilities of department staff.
- d. When the proposed research includes contact with subjects of child abuse information, the research design shall reflect a plan for initial subject contact by the department, which includes the following:
 - (1) Subjects shall be informed in writing of their right to refuse to participate in the research.
 - (2) Subjects shall receive written assurance that their participation in the research will not affect eligibility for services.
 - (3) Department staff shall be advised of research goals and procedures prior to contact with subjects, in order to answer questions which may arise.

(4) Subjects shall receive written assurance that when identifying information is released by the central abuse registry to research staff, the information will remain confidential and that all child abuse information will be deidentified prior to publication of the research findings.

175.42(3) Approval procedures. Procedures for approval of a research proposal are conducted as follows:

a. The supervisor of the central abuse registry shall designate a person to be the single point of contact (SPOC) for all research proposals requesting child abuse information or involving department staff who provide child protective services. All proposals shall be routed to the SPOC at the Division of Adult, Children and Family Services, Department of Human Services, 1305 E. Walnut Street, Des Moines, Iowa 50319-0114.

b. Having received a research proposal, the SPOC shall log the date the proposal was received and other identifying information about the researcher and the research design and shall convene a research advisory committee to review the proposal. This committee may consist of:

- (1) The unit supervisor of the child and dependent adult abuse registry, when applicable.
- (2) The unit managers for the programs addressed by the research proposal.

(3) The research specialist.

(4) Representatives from the field, including a service area manager or designee and one representative from a service area, appointed by the service area manager, if a specific service area is involved.

(5) A representative from the department's division of data management, when the proposal involves use of one of the department's computerized data systems.

(6) A representative of the attorney general's office, when the proposal involves legal questions or issues.

(7) Other persons whom the SPOC may designate to assist in the review.

c. The SPOC is responsible for ensuring that advisory committee members receive copies of the research proposal.

d. The advisory committee may meet in person or by teleconference.

e. The researcher may, at the discretion of the SPOC, be provided an opportunity to address the advisory committee concerning the research proposal and answer questions about the research design.

f. The committee shall determine the value of the proposed research and formulate recommendations for acceptance of the proposal (with conditions as necessary) or rejection of the proposal (with rationale for the rejection). These recommendations shall be submitted to the SPOC.

g. The SPOC shall transmit the committee's recommendations, with additional comments and recommendations, as needed, to the division administrators for the divisions involved.

h. The division administrators shall review committee recommendations and submit the research proposal to the director or designee for final approval.

i. After review by the director, the proposal shall be returned to the SPOC, who shall notify the researcher of the director's decision, which decision shall be final.

j. If the research proposal is approved, the SPOC shall prepare a written research agreement with the researcher which provides:

(1) The purpose of the research.

(2) The research design or methodology.

(3) The control of research findings and publication rights of all parties, including the deidentification of child abuse information prior to publication.

(4) The duties of all parties in conducting the research.

(5) The transfer of funds, if applicable.

k. The SPOC shall be responsible for securing written approval of the research agreement from the attorney general's office, applicable division administrators, and the researcher.

l. The SPOC shall be responsible for maintaining the research agreement throughout the research project and renewing or modifying the agreement when necessary.