

Gladys Carrión Commissioner

Andrew White Deputy Commissioner Division of Policy, Planning and Measurement

Brian Clapier Associate Commissioner Office of Research and Analysis

150 William St, 17th Floor New York, NY 10038

Research Proposal Submission Guidelines

The ACS Research Review Committee reviews all proposals for research involving children and families served by ACS. Research involving staff, foster parents, and contract agencies is also subject to review by the Committee. This includes Bachelors, Masters, and graduate level student research projects. Research involving only case records or other data may be eligible for an expedited review. Federal Regulations concerning the use of children or other designated vulnerable persons may restrict the type of research conducted with children and families whom ACS serves. The Committee is chaired by a designee within the Division of Policy, Planning, and Measurement (PPM). Membership represents many disciplines within ACS.

Items Required for Submission

A complete copy of your research proposal is required. This must include:

- 1) Project title, researcher's name and organizational affiliation;
- 2) Project description and literature review covering your topic area;
- 3) Research question/hypothesis;
- 4) Design and methodology including where the research will be conducted, limitations and how cultural sensitivity issues will be addressed. Medical research should indicate drugs, duration, and dosage for both control and experimental groups. Double blind studies are not permissible;
- 5) Sampling method including power analysis, where appropriate. It is very important to include specific reasons why this population of children was selected. The sample cannot include unfounded cases;
- 6) Data analysis plan, including specific statistical tests to be used;
- 7) Potential benefits for ACS, both for children and families served by ACS and/or the administrators, supervisors, or other staff of ACS;
- 8) Reference list, copies of all surveys, scales, consents, letters of introduction, and interview protocols to be used, and any translations;
- 9) A letter of support from your sponsoring institution inclusive of a notarized copy of your institution's IRB approval document as well as the telephone number and title of your sponsor;
- Procedures to obtain and document informed legal consent, and for children voluntary assent. Details concerning how non-custodial parents will be contacted;
- 11) Specify a plan for reimbursement of travel and other associated costs of participating in the study;
- 12) Procedures to maintain confidentiality;
- 13) Curriculum vitae of the principle investigator and all members of the

research team;

14) Funding sources for your project; attach a copy of the sponsored project proposal/application if relevant to your funding source.

Committee review or approval does not guarantee consent from contract agencies, nor does approval guarantee that consent will be obtained from children for whom ACS has legal responsibility or any individual parents or children who are clients of ACS. Responsibility for obtaining consent from subjects lies with the researchers.

Any services that a client receives as part of a research project that are not ordinarily covered in ACS's contracts will not be reimbursable by ACS. Researchers are responsible for all costs associated with their research.

Federal Restrictions

Federal regulations CFR 46.409, include certain restrictions which apply specifically to wards of the State involved in research. These regulations include:

- a) Wards of the State cannot be used as subjects in research involving greater than minimal risk in which there is not benefit either directly to the child or to the class of children who are wards. An exception to this rule may be when the majority of the sample does not consist of wards, but the child's school, camp, hospital, or other similar institution that has been selected to participate in research.
- b) Wards of the State cannot be selected as the majority of subjects in a study solely on the basis of their convenience to the researcher, regardless of the cost entailed in obtaining subjects from another population

GUIDELINES

General Research Standards

The purpose of the study should be clearly stated and demonstrate the promise of producing, confirming, or otherwise advancing the knowledge base of child welfare.

Include synopses/purpose of the project including historical data, table size, selection and error rate, length of time of study, power analysis, error rate confidence interval based upon the type of data to be collected, etc. Show sufficient sample size, development of control groups, objective data collection instruments, and adherence to proper research procedures.

Describe how and where data will be collected, who will collect the data, under what conditions interviews will be conducted (when applicable); if interviews are required, the provisions that will be made for foreign language participants, etc. (The project or sampling frame must not compete with existing or approved research projects.)

Describe provisions for debriefing appropriate ACS staff on findings of the study and for sharing final products with ACS.

Confidentiality

The safeguarding of our client's confidentiality is mandated by statute. Accordingly, all personally identifying client information must be protected. A researcher may not have access to such information except under certain circumstances set by law. The researcher must obtain prior written approval from the New York State Office of Children and Family Services (NYSOCFS) in order to have access to confidential client specific information. Access, when granted by OCFS, is only accorded to the researcher and admonishes the researcher not to re-disclose client identifying information. Your submission should:

- Describe procedures that will maintain anonymity of respondents including a description of any circumstances which would require identifying the respondent.
- Describe security procedures for storing data and preventing unauthorized access.
- Include assurance that data will be presented only in aggregate form or so as to prevent the identification of any particular individual.

HIV and Drug Program Information

Please be aware that HIV and Substance Abuse Program Information is never accessible unless the researcher obtains consent in writing from the individual participant. Consequently, without the participant's signed authorization, that information will be deleted from the record before it is released to the researcher.

Unfounded Cases

Please be aware that unfounded reports of abuse or neglect cannot be made available for any research purposes.

Client Protection

A prospective researcher is required to specify exactly how he or she plans to protect the client's confidentiality once permitted access.

Support

Include Letters of Support from parties immediately involved in or affected by the research.

Impact

Committee approval will be extended only to proposed research that is of sufficient value to program areas to justify the time, space and staff that ACS participation may require.

Additional Standards for Research Involving Human Subjects

The research protocol must meet the following criteria:

- a) poses minimal risk¹ to children and families
- b) assures that the safest procedures will be used and are consistent with sound research design and methodology;
- c) assures that appropriate safeguards have been included to protect vulnerable subjects;
- d) demonstrates that informed consent is adequate and appropriately documented;
- e) assures the privacy rights of children and families and maintains confidentiality of records;
- f) where appropriate, makes adequate provision for monitoring the data collected to ensure the safety of subjects; and
- g) assures that the subjects will be selected in an equitable manner.

Informed Consent

The consent form must inform the participant of exactly what his or her participation will involve and the overall length of time he or she will be expected to spend.

The consent form should be written in a language that the participant is fluent in and must be at an appropriate reading level for all participants (or the

¹ Minimal risk must not be greater overall than would be normally encountered in the daily lives, routine medical, or psychological care of a comparable group of New York children for whom ACS is not legally responsible. ACS recognizes that abused, neglected, dependent and other children for whom ACS is legally responsible and their families may already be psychologically or physically disadvantaged compared to the general population of children and families. Therefore, the minimal risk requirements for these children and families may be more stringent than for the general population.

participant's legally authorized representative); the generally recommended reading level is no higher than 11th grade. The following elements must be included in the consent form: (a) identification of the research project; purposes, duration and procedures; (b) reasonably foreseeable risks or discomforts; (c) reasonably expected benefits to the participant or others; (d) alternative procedures or treatments, if any, that might be advantageous to the participant; (e) extent of confidentiality to be maintained; and (f) whom to contact for answers to questions about the research, participant's rights, and research-related injury. The consent form must state that participation is voluntary and that refusal to participate will not result in any penalty or loss of service. Participants should be informed that they are free to withdraw from the study at any time. The proposal should describe procedures used to determine the participant's understanding of consent.

Research investigators are responsible for obtaining consent to participate from any subject age 18 or older. If the subject is under the age of 18, consent must be obtained from parents who retain guardianship of any child to be involved in the research. If the child is residing with foster parents, they must be informed about the research; however foster parents can never consent for foster children in their care. In the case of children who have been freed for adoption (i.e. parental rights have been surrendered or terminated), consent must be obtained from the Commissioner of ACS, their legal guardian.

Please Note:

- 1. A written consent form is not necessary in the case of anonymous data collection.
- 2. Interviewing unionized employees may also necessitate obtaining consent from the employee's labor union.

Informed Consent for Non-English Speakers and Persons who are Illiterate

Those who do not speak English should not be categorically excluded from participating in the study. In such cases, unless the principal investigators are fluent in the language of the participant, a translator must be included in the consent process. The translator must sign his or her name at the end of the consent form. In addition, the participant must be given a translated version of the consent form. If the participant is illiterate, or if no translated consent document in the participant's language is reasonably available, arrangements must be made to obtain verbal consent. Illiterate persons who understand English may have the consent form read to them and make a "mark" on the participant's signature line. In such situations, signatures of the witness to the consent process and the person conducting the consent interview are required.

Assent of Children

Research studies involving children who are old enough to understand and agree to participate in the study should include an assent form. This would be in addition to, not in place of, the consent form. [The IRB has determined that this would ordinarily include all children ages eight to seventeen.] The assent form should be written in simple language, appropriate for a child. It should include the purpose of the study, benefits to ACS and the child, risks and discomforts, and procedures of the study. The child should understand that he/she can choose not to be in the study at any time and there will be no punishment for not participating. Whenever possible a verbal assent should be obtained from children younger than age eight.

Use of Foster Children in HIV/AIDS Related Research

Information pertaining to confidential HIV related information is protected by New York State Law. Article 27 F of the Public Health Law prohibits further disclosure of this information without specific written consent of the person to whom it pertains, or as otherwise permitted by law. Any unauthorized disclosure in violation of New York State law may result in a fine or jail sentence or both. A general authorization for the release of medical or other information is not sufficient authorization for further disclosure.

Use of Experimental Drugs

In general, ACS will not permit the use of experimental drugs in research. These rules do not apply on an individual case basis. Such case decisions do not fall under the Institutional Review Board unless the case is part of a research project. The enrollment for ACS approved clinical trials is outlined in Bulletin 98-2/Procedure 101.

Double Blind Studies

The Institutional Review Board does not allow the use of double blind studies in medical research due to the vulnerable nature of the children and families served by ACS.

Pending Litigation

The release of any information that concerns ACS's pending litigation must be reviewed by the ACS Division of Legal Services to determine accessibility.

SUBMISSION PROCESS

Time Frames and Procedures for Review and Notification

a) Within approximately three weeks of receiving a proposal, PPM will contact

you to discuss your project, any required modifications and when the review process may be expected to be concluded. Contact Information:

Brian Clapier
Associate Commissioner
Office of Research and Analysis
Division of Policy, Planning, and Measurement
150 William Street, 17A1
New York, NY 10038
(212) 341-2684
ResearchReview@acs.nyc.gov

b) Upon Committee approval, PPM will draft a letter of support to the State Office of Children and Families (OCFS). You are responsible for submitting your proposal to OCFS, but OCFS will not approve it without prior ACS approval. Contact Information:

Rebecca Colman, Ph.D.

NYS Office of Children and Family Services
Bureau of Evaluation and Research
Room 323/North Building
52 Washington St
Rensselaer, NY 12144
(518) 474-9426
Rebecca.Colman@ocfs.state.ny.us

OCFS approval is necessary when any client-specific information is to be obtained from either case records or interviews. Once you have a letter of support from OCFS, you must submit this letter to PPM before beginning work.

- c) Once your project is in process, any method changes must be approved by ACS.
- d) ACS requires that you submit a draft copy of your work to PPM for review prior to any type of publication.