

IX. Research and Research Utilization Policy

"Research is a systematic and detailed attempt to discover or confirm facts relating to the problems associated with developmental disabilities. Research utilization includes the dissemination of research findings and the use of such findings to improve services for developmentally disabled individuals. (Standards for Services for Developmentally Disabled Individuals, Joint Commission on Accreditation of Hospitals, 1978, p. 121).

A. Involvement in Research

1. Policy

Family Outreach, Inc. will participate in research activities that have direct application to providing services to children and adults with developmental disabilities and their families.

The Board must approve a research proposal before research efforts can start.

Any staff member with research expertise or under the direction of an individual (within or outside of Family Outreach, Inc.) with necessary competencies will be encouraged to engage in appropriate research projects as long as it does not interfere adversely with providing services.

Qualified researchers outside of Family Outreach, Inc. will be encouraged to conduct appropriate applied research (i.e. research which may further efforts in providing services to children and adults with developmental disabilities and their families).

Staff will be contacted regarding research proposals and research activities.

2. Procedures

- a. Any qualified individual may develop a research proposal which may enhance the services provided to children and adults with developmental disabilities or their families. The proposal should be taken to the Program Manager.

- b. The Program Manager will review the proposal for its applicability to Family Outreach, Inc. and the qualifications of the individual(s) submitting the proposal. (If the proposal is submitted by someone outside of Family Outreach, Inc., the Director will serve as the liaison.)
- c. If the proposal appears appropriate, the Program Manager will discuss the proposal with Staff, specifying who may be asked to participate and what may be required.
- d. If appropriate Staff Members (ones who would be involved in research activities) support the proposal, then the Program Manager will submit the proposal to the Director (with the assistance of the individual(s) initiating the proposal).
- e. The Director will then submit the proposal to the Board (with the assistance of the individual(s) initiating the proposal).
- f. The Board will review the proposal to determine its applicability to Family Outreach, Inc. The discussion of applicability will cover, but not be limited to: resources required, specification of emergency procedures, formation of a research committee, and protection of client rights.
- g. The Program Manager will provide research status reports to the Director, the Board, and Staff.

B. Research Committee

1. Policy

Any research proposal approved by the Board, will be monitored by a research committee.

The research committee will include individuals from within and outside of Family Outreach Inc. Expertise in areas relevant to persons with developmental disabilities and research competencies are requirements. The Committee will be composed of the Director (or his/her designee) and at least two other individuals.

The research committee will review the proposal for adequacy of the research design, following appropriate ethical standards, and following appropriate laws and regulations.

The research committee will monitor the research activities.

2. Procedures

a. The Director (or his/her designee) along with the individual submitting the proposal will recruit a research committee.

b. The research committee will review the proposal for adequacy of the research design, compliance to ethical standards and pertinent laws and regulations. If a proposal needs to be modified, the committee will assist the originator in making the requested modifications.

c. Staff would be informed of the status of the proposal.

(1) The research committee would review the research activities at least once a month until the research is complete. The research committee would review the results of the research activities.

C. Program Review Committee

1. Policy

The Program Review Committee will review the research proposal to ensure that the rights and welfare of the subjects are protected and informed consent to participation in research is obtained by appropriate methods.

2. Procedures

- a. The Director (or his/her designee) will schedule a meeting for the Committee to review the proposal.
- b. The individuals involved will obtain informed consent from the research subjects. (If the subject is a child, consent will be obtained from the parents or guardian.) Informed consent includes, 1) an explanation of the procedures to be followed, including an identification of those that are experimental, 2) a description of the attendant discomforts and risks, 3) a description of the benefits to be expected, 4) a disclosure of appropriate alternative procedures that would be advantageous for the subject, 5) an offer to answer any inquiries concerning the procedures, and 6) a statement to the subject that he or she is free to withdraw his or her consent and to discontinue participation in the project or activity at any time. Informed consent should be explained/written in language that the individual giving consent can understand, does not in any way waive the rights of the subject and does not release individuals/agencies involved from liability for negligence.
- c. The process in Step (C, 2, b.) will be reviewed with each research proposal or at least annually.
- d. The Committee will review the proposal to ensure that the rights and welfare of the subjects are protected and informed consent is obtained by appropriate methods.

D. Research Dissemination

1. Policy

The principal investigator will keep the research committee informed of the status of the research.

The principal investigator will summarize the outcome of the research in a written form.

The principal investigator will inform Staff of the outcome and possible application of the research findings.

2. Procedures

a. The principal investigator will maintain communication with the research committee on at least a monthly basis.

b. Once the research is completed, the principal investigator will summarize the findings in writing.

c. The written summary will be disseminated to Staff, the Board, Program Review Committee, and the Research Committee.

d. The principal investigator will inform Staff of the outcome and possible application of the research findings.

e. Family Outreach, Inc. will encourage the publication of research findings.