

## **Lutheran Social Services (Upbring)**

### **Family Services Policies and Procedures**

August 2016

No. 1012

#### **Research, Publicity and Fund-Raising Activities Involving Clients & Protections**

- 1) Purpose: To establish policy regarding requests by educational institutions or other agencies for subjects to participate in research projects.
- 2) Scope: This policy provides the requirements and outlines the procedure for Upbring client participation in research, publicity or fund-raising activities.
- 3) Policy: All requests for projects are cleared through the Senior Vice President for Program Operations and the Agency's internal review process.
  - a. Participation Process:
    - i. Notification to the clients that have been approved to be participants and/or their parent/conservator describing the research to be conducted and advising the prospective participant and/or parent/conservator of the participation process. The letters advise the individual and/or parent/conservator or family:
      1. Of the institution/agency conducting the research;
      2. Purpose of the research;
      3. Voluntary nature of participation;
      4. Clear description of possible risks or discomfort; and
      5. Guarantee of confidentiality.
    - ii. Names and addresses of the participants are not provided directly to the researchers. The letters request that persons wanting to participate in the research to respond directly to the research team and not through Upbring to avoid any perception of coercion.
    - iii. The Senior Vice President for Program Operations consults the Code of Federal Regulations 45 CFR§46.4.09 and 21 CFR§50.56 prior to approval for research involving children and/or youth in the conservatorship of the Department of Family and Protective Services (DFPS). These regulations specify who can participate and requires that an advocate be appointed for each participating child.
    - iv. If Upbring is conducting research, each participant and/or parent/conservator signs a consent form stipulating:

1. Participation is voluntary;
      2. Services are not denied or altered if participation is declined;
      3. Nature and purpose of the research;
      4. Description of possible risks or discomforts; and
      5. Guarantee of confidentiality.
    - v. No person is identified as a research participant. Names or descriptive situations are not used that might identify the client as a participant in the analysis of the research, in the compilations of the data, or in reports promulgated as a result of the research.
    - vi. Upbring follows procedures governing the use of modest incentives for attracting and retaining participants.
  - b. **Publicity Protections:** Requests for a client of Upbring Family Services to participate in any public event to speak on behalf of Upbring in anyway or have the client's personal story, photo or a video of the client used for publicity purposes must be discussed with the client and/or parent/conservator prior to any such event or activity. If the client and/or parent/conservator consent to such participation, the client and/or parent/conservator will be required to sign the consent for publicity/publication form prior to the event or activity. The signed consent form must be filed in the client's record.
  - c. **Fund-Raising Protections:** Requests for a client of Family Services to participate in any fund raising event or activity on behalf of Upbring must be discussed with the client and/or parent/conservator prior to any such fund raising event or activity. If the client and/or parent/conservator consent to such participation, the client and/or parent/conservator will be required to sign the consent for fund-raising activity form prior to the event or activity. The signed consent form must be filed in the client's record.
  - d. **Annual Review of Protections:** Upbring management, with the involvement of the governing body, conducts an internal assessment of the overall risk at least annually that includes:
    - i. Contracting practices and compliance;
    - ii. Research involving program participants and other client's rights issues;
    - iii. Security of information, including client confidentiality; and
    - iv. Fund raising activities and practices.
- 4) **Responsibility:** Revisions to this policy are made at the direction/discretion of the Senior Vice President of Program Operations. Policy is executable through August 2018, unless applicable standards or contractual changes require revision prior to that date. Upbring's Board of Director's reviews this policy annually.
- 5) **Guidelines:** As set forth in this policy.

6) References:

- a. Texas Department of Family and Protective Services, Minimum Standards for Child Placing Agencies, §749.1113.b (3) & §749.1113.b (3) (a) & (b).
- b. Committee on Accreditation of Rehabilitation Facilities, Child and Youth Services Standards, 1.K.2.g.
- c. Residential Child-Care Contract, No. 200322-901.

7) Revisions: Replaces Policy No 101.12 dated September 1, 2008.