

Policy Number: 08-004

Date Approved: 2/10/2021

Executive Responsibility: Executive Director

Policy Title: Policy on Research Studies

Policy Covers: All employees, contractors, and volunteers of The Arc of King County

Policy Purpose:

In line with The Arc of King County's Articles of Incorporation that promote research that enhances the wellbeing of people with developmental disabilities and their families, this policy outlines the ways in which The Arc may engage in research studies and share research studies related to developmental disabilities with the community.

Scope of the Policy:

This policy includes all aspects of The Arc of King County enterprise including employees, contractors, and volunteers doing work on behalf of The Arc, and the developmental disability community we serve.

Policy:

Regarding The Arc's participation in Research Studies

The Arc of King County may be asked to partner in a research study. The Executive Director must approve The Arc's involvement after communicating with the Principal Investigator, clearly understanding the goal and methods of the study, the role of The Arc, and ensuring the study meets the below Code of Ethics.

The Arc's involvement in the research study may include consulting on research design, disseminating information to the community, study participant recruitment, or other activities as deemed appropriate by the Executive Director.

Employees, contractors, and volunteers will never be required to participate as study participants as a condition of their employment or volunteerism. The choice to participate in a research study can only be made by the individual or their legal representative. Employees, contractors, and volunteers cannot be made to feel pressured to become a participant in a research study and cannot experience retaliation from anyone representing The Arc for their choice to or not to participate.

Regarding Research Studies not connected to The Arc of King County

The Arc of King County's policy regarding research studies is to provide information about studies to individuals and families so they are aware of the possible ways they can participate in research related to developmental disabilities, caregiving, and related subject areas. The Arc will solicit appropriate information from the individual or organization conducting the study to ensure it is operating within our

Code of Ethics (see below), however The Arc of King County does not endorse, nor is it involved with, any of the research study opportunities listed.

The following information is included on The Arc's website where we list research studies related to developmental disabilities.

For Individuals and Families participating in research studies: The Arc of King County maintains a list of research studies pertaining to developmental disabilities. When a research team requests we share their study with the community, we include them in the list. If we do not receive a request, we will not include the research study. The Arc of King County does not endorse any of the research studies listed, nor are we connected with the studies in any way. We provide basic information about studies for community access. Each study description includes a contact person to connect with for questions.

For Researchers: Many universities, research centers, and other organizations ask The Arc of King County to help recruit study participants for various research projects pertaining to developmental disabilities. At this time, The Arc rarely partners with research projects, however, with detailed information about the study, we are willing to post information on our website and other communication materials. We do not endorse any research study. If you would like The Arc to include your research project on our website and in other communications, please submit the following information to ask@arcofkingcounty.org:

1. Name of the study
2. Principle Investigator
3. Research institute or organization
4. Basic description of the study
5. Clear description of desired participants (e.g. age, gender, diagnosis, language/cultural group, etc.)
6. Detailed description of participants' commitment, activities, and reimbursement
7. Timeline for study (projected start and end date)
8. Any other relevant information
9. Contact person for this study
10. Website address

Code of Ethics – Expectations for All Researchers, regardless of Study's connection to The Arc.

1. **Honesty.** Strive for honesty in all scientific communications. Honestly report data, results, method and procedures, and publication status. Do not fabricate, falsify, or misrepresent data. Do not deceive colleagues, research sponsors, or the public.
2. **Objectivity.** Strive to avoid bias in experimental design, data analysis, data interpretation, peer review, personnel decisions, grant writing, expert testimony, and other aspects of research where objectivity is expected or required. Avoid or minimize bias or self-deception. Disclose personal or financial interests that may affect research.
3. **Integrity.** Keep your promises and agreements; act with sincerity; strive for consistency of thought and action.

4. **Carefulness.** Avoid careless errors and negligence; carefully and critically examine your own work and the work of your peers. Keep good records of research activities, such as data collection, research design, and correspondence with agencies or journals.
5. **Openness.** Share data, results, ideas, tools, resources. Be open to criticism and new ideas.
6. **Respect for Intellectual Property.** Honor patents, copyrights, and other forms of intellectual property. Do not use unpublished data, methods, or results without permission. Give proper acknowledgement or credit for all contributions to research. Never plagiarize.
7. **Confidentiality.** Protect confidential communications, such as papers or grants submitted for publication, personnel records, trade or military secrets, and patient records.
8. **Responsible Publication.** Publish in order to advance research and scholarship, not to advance just your own career. Avoid wasteful and duplicative publication.
9. **Responsible Mentoring.** Help to educate, mentor, and advise students. Promote their welfare and allow them to make their own decisions.
10. **Respect for Colleagues.** Respect your colleagues and treat them fairly.
11. **Social Responsibility.** Strive to promote social good and prevent or mitigate social harms through research, public education, and advocacy.
12. **Non-Discrimination.** Avoid discrimination against colleagues or students on the basis of sex, race, ethnicity, or other factors not related to scientific competence and integrity.
13. **Competence.** Maintain and improve your own professional competence and expertise through lifelong education and learning; take steps to promote competence in science as a whole.
14. **Legality.** Know and obey relevant laws and Institutional and governmental policies.
15. **Human Subjects Protection.** When conducting research on human subjects, minimize harms and risks and maximize benefits; respect human dignity, privacy and autonomy; take special precautions with vulnerable populations; and strive to distribute the benefits and burdens of research fairly.

Related Policies: None

Approval:

Approved by: Robin Tatsuda, Executive Director

Date: 2/10/21