

Ethical Practice



Principles and Guidelines for Research with Vulnerable Individuals and Families

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The Centre for Children and Families in the Justice System of the London Family Court Clinic is a non-profit social service agency committed to advocate for the special needs of children and families involved in the justice system.

Our clinical work includes assessment of youth in conflict with the law, counselling with high-need youth in residential programs, support of children called to testify in court, mental health assessments in the context of child custody disputes, expert testimony for criminal and civil litigation, and parenting capacity assessments for child welfare agencies.

The Centre promotes safer communities by integrating research and practice. We undertake research suggested by our work with children and families, to refine service delivery, identify and fill knowledge gaps, develop new programs, and recommend policy or law reforms.

Where permitted by funders of the studies, results are made public in a variety of formats tailored to audiences that include families, others practitioners, academics, policy makers, and legislators.

We use a variety of quantitative and qualitative methodologies that have ranged from focus groups to a large-scale, multi-site randomized field trial. Other examples are program evaluations and audits, national program surveys, literature reviews and syntheses, questionnaires, and interviews.

These principles pertain to research in which individuals directly participate or agree to the use of archival information about themselves. In most cases, this involves interviews, surveys, or reviews of file information. The principles guide

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Highlights

- the Centre strives to promote safe communities by integrating research and practice
- we conduct research suggested by our work with families involved with the legal system
- most of our empirical research is conducted with the co-operation of children or families who are vulnerable because of age, trauma history, emotional fragility, institutional status, or involvement with the legal system
- also of concern in some cases is the potential for an appearance of exploitation and conflict of interest
- for these reasons, the standard principles of ethical research practice are augmented
- these principles will govern the design and operation of all Centre research where individuals are directly involved

More information on research at the Centre can be found at www.lfcc.on.ca/resserv.htm

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study design, definition of a pool of potential subjects, contacting subjects, seeking their participation, safe handling of the information collected, and dissemination.

While others may find these principles helpful, this document is not a prescriptive. It is a reflection of the values and principles of the Centre and an articulation of how those values will be put into practise in our setting and when collaborating with sister agencies on research.



Developing the Guidelines

These ethical guidelines are in harmony with our research principles (see Figure 1) and consistent with all professional and ethical codes of conduct to which we must adhere as practitioners and as researchers.

Professional Obligations to Clients

The Centre, being a multi-disciplinary team of professionals, must adhere to stringent standards of clinical practice. The current and on-going welfare of our clients is the paramount obligation of our work, both in clinical intervention and in research.

Our regulatory bodies demand of us, and we demand of ourselves, professional competence, integrity, individual responsibility of all team members, high quality of service, respect for the dignity of individuals, safe handling of files, and stringent safeguards on privacy.

These and other practices are outlined in the accreditation standards for programming, staffing and management of Children's Mental Health Ontario. An even higher standard of responsibility is reflected in the codes of conduct of the Ontario College of Social Workers and Social Service Workers and the College of Psychologists of Ontario. These bodies process complaints from aggrieved parties and discipline members for professional misconduct.

Codes of Ethics

These guidelines were also developed to be consistent with respected professional authorities on research ethics, including the American Psychological Association and Canada's Tri-Council Policy Statement of Ethical Conduct for Research Involving Humans (of the Medical Research Council, the Natural Sciences and Engineering Research Council, and the Social Sciences and Humanities Research Council). The principles hinge on the widely accepted concepts of respect for the dignity of research subjects, voluntary participation, informed consent, confidentiality, anonymity, and avoidance of harm.

Feminist Principles

Our work is further influenced by feminist principles of research. We strive to give a voice to participants, recognizing them as the true experts on the topic under study. When so many of our research participants will have experienced abuse in primary relationships, we must be especially careful not to reproduce a dynamic of power imbalance and control.

We try to appreciate their circumstances in the world, crafting methodologies to help them tell their stories in a respectful and time-efficient way. We pay expenses associated with involvement (e.g., child care) and seek funding for honoraria payments in all proposals. Participants will have free access to research results.

This feminist orientation means cultivating partnerships among community agencies and being respectful of time demands, and compensating partner agencies for providing their expertise. Other agencies may have information needs that differ from ours that should be accommodated.

The design and conduct of research must be sensitive to age, gender, culture, ability, language, sexual orientation, and mental health status. We strive to appreciate the challenges and perspectives of participants and will use non-judgmental and non-pejorative language when describing their situations.

Finally, to share the knowledge, research reports will be available on the Internet in formats that address the needs of stakeholder groups. Instruments designed for a study but of potential use to others will be made available, to advance our collective understanding by encouraging the collection of similar data by others.

Legal Requirements

Statutory and regulatory directives govern access by researchers to some third-party and confidential information about specific individuals. Given the nature of our work, such information might include records related to criminal charges, mental health interventions, or school performance.

Prior written consent will always be sought before accessing confidential third-party information. Depending upon the type of record, this action may be necessary but not sufficient.

Custodians of confidential records must safeguard the privacy interests of individuals and rightly demand that access is gained only through a process that protects their rights.

Figure 1: Research Principles of the Centre for Children and Families in the Justice System

We undertake to:

1. seek funding for, and engage in, research that is suggested by clinical practice and gaps in available services which, in turn, can inform improvements in our service delivery and program development
2. adhere to all standards for the ethical treatment of research subjects including informed consent, voluntary participation, confidentiality, and anonymity
3. be gender, culturally and developmentally sensitive in the design and conduct of all our research
4. provide appropriate referral or treatment of research participants who are identified as being in crisis or needing a mental health intervention
5. reimburse research subjects for their time and out-of-pocket expenses for participation in our research
6. treat research subjects with respect, attend to their privacy interests and chose methodologies that are not unduly demanding of their time
7. communicate and distribute research results in language and formats which are accessible to practitioners, clients, policy makers and legislators
8. identify the implications of our research findings for legislative and policy reforms and work cooperatively with community partners to communicate those implications to relevant officials
9. consider the potential for unintended consequences of laws, policies and programs as well as the benefits
10. develop training programs and professional development activities that enable us to share the knowledge we learn from our research with others
11. provide information to the general public through speaking engagements and free access to information through our web site
12. add to the advancement of the discipline through publication of research results

Where required, in addition to securing consent from individual participants, the Centre will enter into research agreements with the custodians of confidential records and endeavour to secure the prior consent of the appropriate oversight body. This may require compliance with the relevant provisions of the *Freedom of Information and Protection of Privacy Act (R.S.O. 1990, c. F.31)*, the *Municipal Freedom of Information and Protection of Privacy Act (R.S.O. 1990, M.56)*, or the *Child and Family Services Act (R.S.O. 1990, C.11)*.

When youth court records are concerned, a third step is required by law. Access to information about the processing of young people through the Youth Justice Court must be secured with judicial consent.

Augmenting the Standard Safeguards

Given the nature of our work and mandate, our empirical research usually involves the participation of children and families who have experienced trauma or who have been involved with the legal system. Well understanding their

needs and vulnerabilities, we believe it is imperative that standard ethical safeguards be enhanced. As the Tri-Council Policy states:

Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation and discrimination. Ethical obligations to vulnerable individuals in the research enterprise will often translate to special procedures to protect their interests (1998: i.5).

Indeed, we have strengthened the normal principles for the following reasons.

- **involvement of children**

While children are always asked for consent to participate in research, they are too young to give informed consent. Most parents or guardians make decisions in the best interests of their children, but this does not absolve us of responsibility to ensure that no harm is caused, including no emotional distress.

We will act as parallel decision makers and ensure that children are not asked to participate in a study that is not in their best interests. This means seeking the input of children only when the information cannot be gained in any other way, designing studies to avoid potential distress for children, and assessing the best interests of each individual child after a parent or guardian consents to their participation. In addition, children are never asked to relate details of previous victimization.

- **trauma and emotional vulnerability**

Another reason we must augment standard ethical precepts is that many of our potential research participants will have experienced trauma, including woman abuse, child sexual abuse, and other types of criminal victimization. Indeed, our research projects often seek perspectives on the responses of the social service and legal systems to victimization.

While we know of no harm inherent in discussing events associated with past traumas, we fully recognize how difficult it can be. Comfort levels in discussing past traumas will probably increase with time for most people, but at variable rates. Accordingly, we take the following precautions.

First, all potential participants are approached in a way that requires pro-active effort on their parts to be involved. In other words, a request for participation is made indirectly – in letters, newspaper advertisements, or posters – so people are free to decide whether or not to contact us. Those uncomfortable discussing past events would choose not to volunteer for the study. Moreover, they are free to decline in a non-threatening way, by simply not contacting us.

Second, we begin each interview with a discussion of each person's current situation. In this way, we assess readiness to discuss the events of interest. This is especially important when children are to be interviewed.

Third, each person is reminded at several points that they can decline to answer any question that makes them feel uncomfortable. They are also able to terminate their involvement at any time.

Fourth, only an experienced therapist will interview children. This is also true of adults where the topic is potentially difficult or if we have reason to believe that the person is emotionally fragile for any reason. Therapists will conduct an initial assessment (as just

described), pose questions in a sensitive way, know when a person is uncomfortable discussing any topic, and terminate an interview if signs of distress manifest.

Fifth, we would never involve a participant in a research study if he or she is currently at risk of abuse or victimization. If such information comes to light, we discuss appropriate support resources, assist with referrals and, where appropriate, engage in safety planning. If a child is at risk, the Children's Aid Society will be notified, pursuant to provincial law.

Lastly, as discussed next, we take steps to reduce the likelihood that anyone agrees to participate solely to secure the honoraria payment.

- **financial vulnerability**

As with all research involving human beings, some potential research participants will be struggling to make ends meet financially. The promise of an honorarium could be the reason someone consents to a study they would not be comfortable doing otherwise. Some ethical standards forbid paying research subjects for this reason. We cannot take that stand. Participants deserve to be compensated for their time.

We emphasize that potential participants can decline consent while retaining the honorarium.

- **court-involved participants**

Some people whom we approach for research have been involved with the courts in situations where judges are making decisions of great consequence: criminal sentences, child custody, or child welfare measures which at the extreme end of a continuum can involve termination of parental rights.

While we strive to integrate research and practice, we must clearly demarcate the two when we approach former clients about research. Questions common in such research pertain to perceptions of the legal process, post-intervention outcomes, prospective follow-up, or satisfaction with a service.

When research questions necessitate involving former clients, these safeguards apply. First, we never approach a former client to participate in research until well after any legal proceedings have concluded.

Second, it must be clear that their decision to decline or accept an offer to participate has no bearing on the

service they might receive from the Centre in the future, especially as it pertains to recommendations made to the court.

Third, it must be clear that information collected as part of a research project could be subpoenaed by a court of competent jurisdiction or introduced into a legal proceeding with the written consent of the research participant.

Fourth, records of research data will be held in a secure manner and destroyed in conformity with the policy outlined later in this document.

Choice of Research Topics

We undertake to seek funding for and engage in research that is suggested by clinical practice and gaps in available services which, in turn, can inform improvements in our program delivery and program development. Topics should relate to needs of children and families involved with the legal systems. Preference is given to topics which cross several program areas and/or which have not received due attention in the literature. Our research must be aimed at improving or developing interventions or furthering advocacy and it must have implications for practitioners which can be communicated as professional training, manuals, measurement tools, clinical direction, or other resources.

Ethical Study Design

Based upon the above-listed sources of information, and a review of standard ethical prescriptions from allied disciplines, the ethical principles outlined here will govern the design and execution of all empirical research conducted by the Centre. These principles co-exist with other principles of study design such as cultural and gender sensitivity, and validity of measures.

Children will be directly involved in research only when the information cannot be gained in any other way. Some studies necessarily require hearing their voices and we are committed to letting them tell their stories in the most sensitive and supportive way.

Commitment to Quality Research

We will choose the most appropriate methodology required to study the topic to maximize the utility of the results. Our projects are supported by funders, community partners, and research participants to whom we owe our best efforts to

produce a quality product. To us, this means collecting data that speak to the questions defined by all stakeholder groups. When resources do not permit using a methodology suitable to answer those questions, we will not engage in the research.

It is also crucial to accommodate into research design the ability to uncover unintended negative consequences of policies and interventions. Even programs designed with the best of intentions can have iatrogenic effects that may outweigh the benefits. In an era of limited resources for social services, we should promote interventions from which participants derive the greatest benefit. Quality research can identify such interventions.

Benefit to Participants

Any proposed study must have a clearly articulated rationale justifying collection of the target information, or it will not be undertaken. All research must be grounded in the needs of our clients, to help them and others like them receive a more effective service. As such, the benefit of children and families involved with the justice system is our main goal.

Individuals who participate in our research should also benefit from participation, either because of the financial compensation, increased understanding of their cases, or the opportunity to speak with an experienced therapist. Interviews can reveal unrecognized problems, or parents can be re-assured that their children are coping well.

Deception

The Centre will never engage in research that involves deceiving participants about the true nature of a study. Participants must understand the rationale for the study, what is expected of their participation, and how the information will be used.

Intrusiveness

We will choose methodologies that are not unduly demanding on the time of research participants. Specifically, we frown upon the use of copious numbers of psychological tests and use these measures sparingly. Any tests must be well-suited to the data collection needs, appropriate for the age and education level of participants, and be as short as possible to achieve the desired information.

We will seek only information required to address the research questions. This means, for example, that we might focus on a person's experience as a court witness without needing to know any details of the victimization about which he or she testified.

Protection from Harm

The Centre will never engage in research that might cause physical or emotional harm. There can be no justification for doing so. No research study is so important that it justifies compromising the welfare of individuals.

Given the nature of our work, some participants will be asked about painful events from the past. In these cases, we will take precautions including screening out individuals too vulnerable to participate, ensuring that participants understand the nature of the questions in advance, emphasizing the right not to answer a question that makes them uncomfortable, and engaging in appropriate debriefing and, where necessary, referral to a therapist or other appropriate intervention. An interview will be terminated if the participant evidences discomfort or distress. Any interviews with children will be conducted by experienced therapists.

When we assess that participation is not in a person's best interests, we provide the honorarium and turn the discussion to possible referral to an appropriate service.

Compensation

We compensate all participants with a financial honorarium. The amount should be commensurate with the time required. We cover expenses related to participation including parking and child care. These payments must not be seen as inducements to participate so the honorarium will be paid even if the potential participant declines consent for the study, is screened out of the study after attending for an interview, or if the interview does not proceed because of the assessed vulnerability of the person.

Concessions for Children

When designing studies to involve direct contact with children, we will consider their attention span, level of development, and literacy skills. Questions are asked in language consistent with their age and, when necessary, modified to accommodate cognitive or communication disabilities. As noted elsewhere in this document, we will seek consent to participate directly from them and have in place special safeguards because of their age.

It is our policy, and stated as such up front, to contact parents or guardians the day after an interview with children. We do this to ask about delayed effects of the interview such as trouble sleeping. When necessary, we will conduct a de-briefing interview to assess the situation and see if further intervention is required.

Locating Potential Participants

Strategies to locate potential participants can include advertising in local media, posters hung in public places and/or allied agencies, wide-spread mailing of leaflets, or contacting past clients through the mail.

Strategies to identify potential participants must take into account the potential to engender conflicts of interest, exploitation, or to compromise the privacy interests of individuals. The burden on us is especially high when we seek to involve past clients in our research.

Contact through the Mail

When contacting past clients about research, we approach them with a letter to ask if they would like to participate in a specified research study. Failure to respond to the letter will plainly indicate a desire not to participate.

Precautions taken to preserve privacy include use of envelopes without a corporate name or logo and verification address. In case of mis-direction of the letter to a third party, the content is written so the nature of any service received cannot be discerned.

We never contact a family if a person suspected of abusing any family member has moved in or may have returned to the family.

We never contact potential subjects by telephone. The exception would be if they had signed a consent form indicating that a researcher would call in the future to speak with them.

On-going Legal Proceedings

Recognizing that legal proceedings can be revived in the future, especially when custody of or access to children is at issue, it is our policy never to extend a request for participation to anyone who is involved with a case before the courts. The exception would be a study to monitor cases as they progress through the system and/or ascertaining people's opinions of how their case is being handled by the legal system.

Seeking Consent

Once people indicate an interest in participating in a study, we must provide sufficient information so they can consent or decline participation based upon complete knowledge. Any agreement to participate must be based upon informed consent. In this process, they must be advised of all facets of the study in language that is commensurate with their ages, level of literacy skills and

facility with the English language. They must understand the time commitment, the nature of questions asked, the safeguards for their privacy, and that there are no consequences of declining to participate.

Letter of Information for Participants

Each potential participant must be given a Letter of Information that explains the project in straightforward language. Specifically, these factors must be explicated: title of the project, names of investigators, funders, rationale for the project, intended use of the information, what is expected of participants, the voluntary nature of participation, and safeguards such as anonymity and confidentiality.

It is also important that participants understand the limits to confidentiality. Three circumstances are outlined: learning a child may be at risk for abuse, hearing a threat made about a third party, and the potential for subpoena of the information collected.

The Letter of Information must describe how to contact the researcher and also the Executive Director. People keep the Letter and are directed to contact the Centre if they have any questions or concerns.

Because of the possibility of undisclosed literacy deficits, all information is also explained verbally. For people speaking English as a second language, special care is taken to ensure that the information is conveyed in plain language. If there is any doubt about their understanding, an interpreter is used.

Denial of Service

In some studies, access to a particular service or program must be limited to those who agree to participate in the research project. This is usually true when the funding for a service is provided to test an intervention. In these cases, researchers must be especially vigilant to the possibility that a person might agree to participate in a study only to access the service. One way to safeguard their rights is to ensure that participation in the research is not harmful or onerous and that, as described above, the information collected is used in a responsible way to inform better practice. It is also imperative that those who decline have access to a program of equal quality through another route.

Consent from Children

We will involve children in all aspects of the process including explaining the study and securing their signed consent. In addition, the parent and/or guardian must consent to the child's participation. Where the guardian is

a child protection agency, and where possible and appropriate, a parent will be notified of the child's participation and receive an explanation of the study.

Consent for Access to Third-party Information

Where possible (i.e., if the information pertains to a specific individual), prior written consent for accessing the record will be sought and attained. In addition, all required approvals and agreements will be entered into with the custodian of the records, including in most cases a signed research agreement. This process applies also to securing clinical records from our own agency.

Handling of Information

Information secured from individuals or from archival sources is held in secure conditions and destroyed in a timely manner.

Confidentiality

Each participant is guaranteed that the information they provide will be kept confidential, absent any of the three conditions outlined in Letter of Information. In electronic statistical data bases, each participant is identified by a case number only. There is one master list containing the concordance of case file and name.

Anonymity

The dis-aggregated responses of participants are never included in research reports. The possible exception is when a direct quotation is used to highlight a point. In such cases, names are never used and any potentially identifying information is obscured or omitted. In any report, the data are presented only in the aggregate.

File Storage

Client files are stored on-site in locked file cabinets. At the completion of the study, superfluous information is shredded and files are transported in a secure manner to a bonded storage facility off-site. Records are catalogued by case number not name so the storage facility does not have a record of the name. The ability to retrieve files is restricted to authorized personnel.

Later Access to Research Records

People who participate in research may, at some point in the future, wish to access the information they provided for purposes of therapy or legal proceedings. We will release the information to them or to designated parties only with their written consent.

Third-party Information

In cases where confidential information is gained from a third party, the same guarantees of confidentiality and safe storage will apply. Material provided by third parties will be destroyed in accordance with the agreement made when the information was secured.

Record Destruction

Files are destroyed five years after the study ends.

General Issues

These issues apply to all projects.

Responsibility

The responsibility to apply these principles attaches to all members of a research team and can only be deviated from with written approval of the Executive Director.

It is the responsibility of the Director of Research to ensure that each team member is fully understand the principles and guidelines articulated here prior to the commencement of contact with potential participants.

External Review

Where a proposed study would deviate from the principles outlined here, an external review will be sought from professionals in our community who have knowledge of the special needs of the group under study and the safeguards required to protect their interests.

In addition, in many cases, research projects are overseen by advisory or steering groups, which will be informed of or consulted about the ethical safeguards of the study.

Insurance

The Centre undertakes to carry sufficient insurance.

Dissemination of Results

We undertake to distribute research results in language and formats which are accessible to practitioners, clients, policy makers and legislators. Each research project will have a web page that explicates the methodology, timelines of the project and links to any reports generated. We will make reports available free through the Internet or in printed form on a cost-recovery basis.

Availability of Data Collection Instruments

Data collection instruments designed for our projects will be publicly available so others can build on our work.

Selected Resources

American Psychological Association (2002). *Ethical Principles of Psychologists and Code of Conduct 2002*. Available on-line at <http://www.apa.org/ethics/code2002.html>

Canadian Research Institute for the Advancement of Women (1996). *Feminist Research Ethics: A Process*/Éthique en matiPre de recherche féministe: Un processus. Ottawa: CRIAW/ICREF.

National Council on Ethics in Human Research (Ottawa) <http://www.ncehr-cnerh.org/>

Office for Human Research Protection, U.S. Department of Health and Social Services <http://ohrp.osophs.dhhs.gov/>

Ontario College of Social Workers and Social Service Workers (2000). *Code of Ethics and Standards of Practice*. Available on-line from <http://www.ocswssw.org/>

Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada (1998). *Tri-Council Policy Statement for Research Involving Humans*. Available on-line at <http://www.nserc.ca/programs/ethics/english/policy.htm>

PRAXIS: Research from the Centre for Children & Families in the Justice System
Ethical Practice
Principles and Guidelines for Research with Vulnerable Individuals and Families
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