

## Appendix C



### Ethical Guidelines for Quality Assurance in Child Welfare



Prepared by: Q-Net: Ontario Child Welfare Quality Network

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**Disclaimer:**

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*QI \*is an integral part of good clinical practice and is designed to bring about immediate improvements in [care] in local settings.*

*C. Grady, 2007*

*The social arrangements that normally hold health care professionals, managers, and organizations responsible for the quality of care should also ensure that they meet requirements for the ethical conduct of QI.*

*J. Lynn et al., 2007*

*\*NB: For the purpose of this document the term Quality Assurance (QA) will also refer to Quality Inquiry (QI)*

## Introduction

Quality Assurance (QA) programs both in health care and human services settings are considered an essential part of ensuring excellence in the delivery of clinical services, that these clinical services meet practice standards, and that improvements are undertaken where indicated <sup>1</sup>. Although much has been done to formalize processes for ethics oversight of research involving human subjects<sup>2</sup>, the nature or extent of ethics oversight necessary for QA initiatives is still under much debate <sup>3,4</sup>. The need for ethical guidelines for QA activities is acutely felt by child welfare organizations as the client population being served is largely non-voluntary and often representative of vulnerable groups within society. There is currently very little literature on ethical considerations for quality assurance activities in the child welfare field which, in Ontario, has been subject to growing demands for accountability and outcome measurement over many years, making QA an even more important organizational responsibility.

This document is the result of a collaborative project of Q-NET, a provincial networking group of the Ontario Association of Children's Aid Societies (OACAS) drawing together professionals that manage or are involved in quality assurance activities within their local organizations. These ethical guidelines are offered as a resource to child welfare organizations. There is a shared understanding within Q-NET that further development and refinement of these ethical guidelines is inevitable and desirable. Accordingly, these guidelines should be viewed as a "living" document that will be subject to review and enhancement in accordance with emerging best practices through the Q-NET community and in the literature as well.

In establishing priorities for the development of ethical guidelines, Q-NET members concurred that the focus would initially be on involvement of service users. Future refinements would

extend application to include other key stakeholder interests, like those of children's aid society (CAS) staff.

QA activities must align with best practice standards to ensure their legitimacy and efficiency. Readers are referred to "Keys to Quality: A Handbook for Building Capacity in Ontario Child Welfare Organizations"<sup>5</sup> as a reference for best practice standards for QA at children's aid societies.

### **Research vs. QA: Why is ethics oversight of QA important?**

Research involves systemic investigation focused on testing a hypothesis or theory, with the ultimate objective of contributing to generalizable knowledge<sup>6,3,10</sup>. The requirements for the ethics oversight of research involving human subjects in Canada are detailed in the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)<sup>11</sup>. These requirements have been thoughtfully developed over decades to protect the interests of subjects<sup>2</sup>. Research with human subjects requires formal ethics oversight by an institutional review board (IRB). To assist children's aid societies when deciding whether to participate in research activities, initiated internally or by outside researchers, the OACAS published "Provincial Best Practice Guidelines for Research Involving CASs"<sup>10</sup> to help agencies examine ethical issues.

Questions are now being discussed in the literature about the need for ethics oversight of quality improvement activities involving humans<sup>1</sup>. Differences exist between the objectives and methods associated with research involving human subjects and QA. A view held by many is that the characteristics that distinguish QA from research is the use of measurement and feedback to change clinical or managerial processes in a particular local setting and the reasonably rapid use of the data to implement improvements<sup>6,3,1</sup>. In addition, QA may be regarded as intrinsic to the practice of child welfare as it is in health and other human services whereas research has no equivalent status.

It is the opinion of many experts that the distinction between QA and research is often hard to discern given the application of common data gathering methods and the potential generalizability of the knowledge acquired through QA activities<sup>1,3,4,7,8</sup>. As well, QA activities may inadvertently cause harm, affect service users unfairly, or waste scarce organizational resources. Consequently, there is general agreement in the literature that some form of ethics oversight for QA is needed and contributors to these guidelines seek to identify what kind is suitable and sufficient.

In child welfare organizations, ethical challenges faced in conducting QA initiatives arise largely from the vulnerability and marginalization experienced by client families, as well as by the mostly involuntary nature of their involvement. These issues of vulnerability, power, and authority strengthen the argument for the development of ethical guidelines for QA.

QA plays an important role in meeting the overarching responsibility to ensure quality care is being delivered to the community by both health care and human services organizations. In conjunction with this duty, organizations are also responsible to ensure that QA activities meet with requirements for ethical conduct<sup>1</sup>.

## **Project Overview**

Staff responsible for collecting and reporting feedback from families involved in services provided by children's aid societies have shared accounts of their efforts from time to time at Q-Net meetings. Over several years, different data collection methodologies have been described, lessons learned have been shared, and initiative has been taken to standardize across agencies some questions posed to families in order to compare and contrast feedback. Agencies have been striving to give voice to families in a credible, regular, and reliable process to bolster quality improvement programs as well as organizational transparency and accountability. As more agencies have attempted "client feedback" surveys, concerns have been raised about procedures related to informed consent for participation and in managing and interpreting feedback from service users and other stakeholders in a timely and meaningful way.

In March, 2011 Q-NET convened an all-day workshop facilitated by a bioethics consultant to address the ethical considerations and challenges currently faced when conducting QA activities in a children's aid society. The aim was to produce for the child welfare sector a document that would instruct and support best practice in quality assurance and that would support public confidence that children's aid societies engage stakeholders respectfully and consistently across the province.

Three all-day workshops with Q-NET members were conducted by the bioethicist and collaboration with the consultant followed on drafting the guideline document.

## Ethical Guidelines

When reading the ethical guidelines that follow, consider that Q-NET identified three key areas of concern for attention:

- i. Approaches currently employed to obtain informed consent from service users for participating in QA activities vary across the CASs. Many challenges have been reported by CASs in identifying best practice. The ethical issues have included (but are not limited to): voluntariness and differences in power that exist between CAS workers and clients; accessibility and timing of information being shared about QA; age and procedures for consent for and by children/youth;
- ii. Questions were raised about whether QA data is being used optimally by organizations to ensure that benefits to current and future service users are being sufficiently realized; and.
- iii. QA programs in child welfare need more organizational recognition and support to evolve. QA is an important contributor to ensuring quality in programs and processes that meet the needs of the community.

**Table 1 Ethical Requirements for the Protection of Human Participants in Quality Assurance Activities**

| Ethical Requirement               | Explanation  |
|-----------------------------------|--|
| <b>Respect for Participants</b>   | <p>QA activities are designed to protect the dignity of participants, including privacy and confidentiality.</p> <p>Participation of vulnerable and marginalized populations imposes a special obligation to protect against unreasonable intrusion, discrimination, and harm. QA activities and procedures not to compromise the best interests of service users.</p> <p>Results from QA activities are communicated in a manner that protects confidentiality and privacy.</p> |
| <b>Value</b>                      | <p>The anticipated gains from a QA activity should justify the resources assigned and the burden and risks imposed on participants.</p>  |
| <b>Validity</b>                   | <p>The data gathering methodology utilized is sound and structured to achieve the QA objectives</p>  |
| <b>Balance Benefits and Risks</b> | <p>Burdens on and risks to participants are to be minimized and mitigated. Potential benefits to current and future service users, the organization, and the community are maximized.</p> <p>Potential adverse effects have been anticipated and procedures are established to reduce, minimize, and eliminate adverse consequences.</p>   |
| <b>Fair Selection</b>             | <p>Participants are selected with regard to fair distribution of the burdens and benefits of QA. Non-inclusion of service users may be based on particular clinical or treatment considerations.</p>   |
| <b>Informed Consent</b>           | <p>All potential participants in a service delivery setting receive general information about the organization’s program of QA activities.</p> <p>Potential participants are provided information about the purpose, process, rights, duties, and potential benefits and risks associated with the QA activity.</p> <p>Participants are informed about the QA activity and decide to participate voluntarily and freely.</p>   |
| <b>Oversight</b>                  | <p>The organization has established processes to ensure the ethical conduct of QA. Each QA activity is reviewed and supervised commensurate with the level of potential risk, value, methodology, and resource demands.</p>  |



### ***Informed Consent***

When QA involves direct contact with service users, a priority concern is the issue of informed consent. The ethical principle of autonomy is a key consideration when obtaining consent from potential participants for QA activities. This principle requires that a capable individual be given timely and appropriate information in order to make a voluntary and informed decision<sup>9</sup>. The information provided about a proposed QA activity should be in a format that is readily available and in language that is easy to understand by the individual from whom consent is being sought. This information should include the likely benefits that will be derived from collecting this feedback- for the participant, future service users, and the organization -as well as the possible risks to the participant. The accessibility of the information, the circumstances of where and when informed consent is being sought, as well as the skill of the person seeking this consent, all have bearing on whether ethical requirements have been met.<sup>5</sup>

### ***Accessibility of Information***

- Use language and presentation formats that are simple, clear, and easily understood by service users and respectful of special needs (i.e. age, literacy, language, vision, etc).
- Describe the organization's commitment to continuous quality improvement and potential benefits and risks of involvement to the participant.
- Make this information readily available to service users, staff, and other stakeholders.
- Provide information to service users repeatedly at optimal junctures in service delivery (i.e. include in a brochure outlining services provided by the CAS upon first contact, transfer to ongoing, completion of service)<sup>12</sup>.

### ***Training and Skill Development***

- Staff providing information about QA to service users should receive sufficient training about the organization's QA program and the process for obtaining informed consent.
- Include information about assessing an individual's capacity to provide consent, the voluntary nature of consent, and when it is optimal and not advisable to discuss QA activities or the need for consent.

## Considerations for Optimizing Informed Consent

- CAS involvement with a family often coincides with or represents a crisis. QA related-activities, including processes related to informed consent, must not compromise the clinical care being provided to the child and/or family in any way or at any time
- Obtaining informed consent from service users is best viewed as a **process rather than as an event.**
- The process of informing service users about the organization’s QA program is best when it begins early and is integrated into the orientation of service users to the services provided by a CAS;
- Conditions under which consent to participate in a QA activity can be withdrawn should be outlined for service users. In addition, circumstances that would limit the removal of individual information from aggregate data should be clarified.
- Seeking informed consent to participate in a specific QA activity at the point at which active service involvement is completed (i.e. service user file is to be closed) optimizes voluntariness.
- Informed consent to participate in a specific QA activity may be given verbally to a worker or may be evidenced by completion of a questionnaire or interview at the time of the request.

## Participation in QA After Service

- For QA activities that involve “follow-up” contact, such as a telephone interview sometime after service has ended, then at the time the file is closed the service user’s verbal consent is sufficient to allow the use of their personal information (i.e. email, phone number, address, social media etc. ) in order to make that future contact. Workers are to advise service users about what future contact procedures are to be utilized, that they may withdraw this agreement for future contact at any time, and that they may refuse to participate in the future QA activity when or if they are contacted<sup>13</sup>. It is suggested that this information also be conveyed to service users in writing as part of the file closing letter.
- Provide workers with an avenue to identify service users who have *not* consented for follow-up contact and those for whom follow-up contact is to be avoided for clinical considerations, such as:
  - active or potential lawsuit against the CAS;
  - active formal complaint (i.e. CFSRB);
  - acute or other serious mental or physical health crisis serious;
  - personal crisis or contentious issue within previous 3 months (i.e. death of a child).

## Youth and Children: Special Considerations

Youth and children are primary stakeholders in all CAS activities and their direct feedback about service is highly desirable. The ethical concerns about mitigating harm or risk warrant serious reflection before a QA activity is developed and a process for informed consent implemented.

- For youth and children living in the community and actively receiving CAS services, the possible risks of harm may exceed the potential benefits. This matter should be considered prior to starting QA activities.
- Parents may assist a child or youth in making an informed decision about participating in a QA activity. However, the child or youth's decision to participate in QA must be based on his/her capacity to make an informed and voluntary.
- Feedback from Children in Care - the youth and children for whom CAS have parental authority - is uniquely important. However, children's aid societies must carefully balance QA activities with this population together with existing demands placed on them through accountability routines implemented directly by government (i.e. annual Crown Ward reviews, Foster Care licensing, post-placement interviews). The assessment of potential benefits and burdens of involvement in CAS QA activities must be favourable from their perspective.

### Is informed consent from service users always required in QA?

Q-NET recognizes that service leaders, clinicians, and managers in child welfare organizations work to improve policies, procedures, and practices to serve the best interests of children and families continuously as such improvements are a professional obligation. Many organizational efforts seek advancements in worker knowledge and competency, documentation, service processes, inter-agency collaborations, and the like. Data gathering methods which do not entail direct contact with service users but which may still draw on information about service users may be undertaken ethically without explicit consent provided that confidentiality is appropriately protected. Examples where these conditions apply include: (i) aggregation and analysis of information routinely documented during service delivery (file reviews); and (ii) review of complaints received from service users.

### ***Maximize Benefits and Minimize Risks***

Direct contact with service users for purposes other than clinical service, including for QA, represents an intrusion and, as such, needs to be warranted.

Potential benefits from QA may accrue to the service user participants but more typically are anticipated for future service users and the organization overall. It is important when planning a QA activity to state clearly what benefits are expected and how they are to be realized. Optimal gains from QA surface in organizations sufficiently resourced to produce, report, and apply results in a timely way.

QA activities may inadvertently affect service users unfairly or cause harm (i.e. duress, emotional distress, disclosure of concerning information). Implementation requires respect for service users and sensitivity to their vulnerabilities so as to protect them.

Firstly, QA activities are never to interfere with or risk in any way clinical service to the children and families. The timing of when to obtain service user feedback must be carefully considered. Although client satisfaction literature generally encourages collection of opinions before or just at the end of active service<sup>15</sup>, approaching those currently receiving protection services may be problematic. The possibility must be considered seriously that service users may experience duress or worry that uncomplimentary responses could negatively affect service outcomes (i.e., access to supports, removal of child, delayed reunification).<sup>14</sup> Assurances that responses are confidential may not fully relieve these concerns. The reliability of the data may reasonably be questioned when collected under these circumstances.

Requests for feedback at the point of service termination may diminish the potential for distress in service users, who may feel more comfortable with options to refuse participation or to voice constructive feedback at that time. In addition, it may be that opinions given after service concludes may be more thoughtful and reflective since it is based on their cumulative experience.<sup>14</sup>

Secondly, organizations need to plan for and be prepared to respond appropriately to address situations where an adverse reaction arises during or subsequent to participation in a QA activity.

At an organizational level, QA activities may waste scarce resources if they are poorly designed or implemented, or if results are not reported or applied in a timely way to make improvements.

## ***Organizational Structure to Support and Sustain QA***

Organizational mechanisms are necessary to support implementation of an effective and ethical QA program. As previously noted, QA is differentiated from research, in part, because of its reasonably rapid application of findings to change and improve services. So, if a research review board model is too slow and onerous for QA, then another approach is called for to ensure participants' well-being is protected.

### Infrastructure

- Statements or policies are important that acknowledge the organizational and professional obligations to pursue improvements in service continuously and that identify the QA program as *"The way we do business at CAS."* Such policies address:
  - A reporting structure through which senior leadership can monitor how well QA activities align with strategic goals, meet ethical requirements, and are utilized to improve service and create value.
  - Procedures or protocols to identify and mitigate risk of harm associated with participation in specific QA activities.
  - Assignment of resources to operationalize the QA program.
  - A deliberative forum to address emergent or urgent ethical challenges that arise through QA.

### Communications

- Brochures and other informational resources through print and other media are created for and used by staff to inform CAS clients about the organization's QA program, including the process for informed consent.

### Partnership with CAS staff

CAS staff will be effective contributors to QA activities when they understand the purpose of the program and have the knowledge and skills to fulfill the QA duties assigned to them, such as those outlined above pertaining to informed consent.

The following will support an effective partnership between QA and CAS staff:

- Educational material and ongoing training is provided to staff to ensure their knowledge and understanding about QA and to guide them in their role of informing clients about QA and in obtaining consent for participation at the time clinical services are terminated.
- Ongoing communication with staff is valuable about QA activities, results, and further development of ethical guidelines.
- A fair and transparent process exists to address situations where service users express during a QA activity concerns about staff performance. Such arrangements are clearly communicated and accessible to CAS staff. While it is important for the organization to be able to address specific concerns raised about staff conduct when reported through a QA event, QA activities are not to be designed as a means to collect information for performance appraisals.
- Staff engaging with service users during QA activities (i.e. providing information, obtaining consent) are gaining valuable experience that is likely to expose unforeseen issues or challenges. By creating a forum for front-line and QA staff to exchange information, such as advisory group for overseeing a QA activity, the partnership will be enhanced and the organization will gain by evolving its QA program.

### ***Ongoing Development & Refinement of Ethical Guidelines through Q-NET***

Q-Net expects to respond to experiences arising from the implementation of these guidelines by sharing experiences, addressing common challenges, identifying innovations and, over time, identifying effective (“best”) practices that will contribute to ongoing development of the ethical guidelines. This may be achieved through discussions at regularly scheduled meetings.

Another potential area for future advancement is the establishment through Q-Net of a deliberative forum (i.e. Ethics Advisory Group) to respond to questions of ethics posed by local agencies engaged in or proposing QA activities. A collaboration of this sort may assist local agencies in activating desirable ethical oversight to QA. It would be in addition to review by local senior managers. At the same time, such a forum could effectively filter “lessons learned” and enhancements to these guidelines.

Specific areas for potential elaboration and refinement are noted below as encouragement to the child welfare sector to continue its exploration of what is and how to apply ethical QA:

- Innovations in utilizing existing avenues of service user feedback, such as independent and spontaneous service user calls to managers about concerns and, in addition, complaints submitted formally through established channels. Harnessing information proactively provided by users eliminates intrusion and minimizes risk. One may posit that the organization has an ethical obligation to optimize the value of that freely offered feedback.

- Ethical challenges arising from service user vulnerability and about how best to conduct QA initiatives with children and youth and developing ways for anonymous feedback.
- Ensuring security and confidentiality (privacy) of data when handling and interpreting and reporting data.
- Ensuring that concerns about possible harm or risk from the dissemination of QA results are carefully considered along with the likely benefits to quality and client service delivery.
- Engaging service users to optimize benefits and mitigate harm in the interpretation and dissemination of QA results.

## References and End Notes

1. Lynn J, Baily M, Bottrell M, Jennings B, Levine R, Davidoff F, Casarett D, Corrigan J, Fox E, Wynia M, Agich G, O’Kane M, Speroff T, Schyve P, Batalden P, Tunis S, Berlinger N, Cronenwett L, Fitzmaurice M, Dubler N, & James B. The Ethics of Using Quality Improvement Methods in Health Care. *Annals of Internal Medicine*. 2007;146:666-673.
2. Guillemin M, Gillam L. Ethics, Reflexivity and “Ethically Important Moments” in Research. *Qualitative Inquiry*. 2004;10:261-280.
3. Lynn J. When does quality improvement count as research? Human subject protection and theories of knowledge. *Qual Saf Health Care*. 2004;13:67-70.
4. Perneger T. Why we need ethical oversight of quality improvement projects. *International Journal for Quality in Health Care*. 2004;16:343-344.
5. Ontario Association of Children’s Aid Societies, *Keys to Quality: A Handbook for Building Quality Capacity in Ontario Child Welfare Organizations*, 2009.
6. McMaster University, Health Research Services, HHS/FHS REB. Quality Assurance. 2012: <http://fhs.mcmaster.ca/healthresearch/reb/qaorresearch.html>
7. Grady C. Quality Improvement and Ethical Oversight. *Annals of Internal Medicine*. 2007;146:680-681.
8. Hagen B, O’Beirne M, Desai S. Innovations in the Ethical Review of Health-Related Quality Improvement and Research: The Alberta Research Ethics Community Consensus Initiative (ARECCI). *Healthcare Policy*. 2007; 2: e164-e177.
9. Beauchamp T, Childress J. *Principles of Biomedical Ethics*. New York: Oxford Press, 2001.

10. Ontario Association of Children's Aid Societies, Provincial Best Practice Guidelines for Research involving CASs, 2008. See page 1: "Research is...any procedure or activity designed to advance knowledge that is not part of the regular accountability systems and routines with the Society."

11. [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans \(TCPS 2\)](http://www.pre.ethics.gc.ca/eng/resources-ressources/news-nouvelles/nr-cp/2010-12-07/), 2010.

12. Here is an example of a general description of a QA program that may be included in a brochure to acquaint new service users with child welfare services: *"We strive to provide to you and your family the most helpful and effective services. As part of that commitment, we operate a Quality Assurance program and gather and assess information, including feedback from families, on a regular basis to help us improve our services."*

13. The Urban Institute, Finding Out What Happens to Former Clients, 2003.

14. Baker, A Client Feedback in Child Welfare Programs: Current Trends and Future Directions. Children and Youth Services Review. 2007; 29:1189-1200.

15. Tilbury C, Osmond J & Crawford M Measuring Client Satisfaction with Child Welfare Services. Journal of Public Child Welfare. 2010; 4:77-90.