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Article abstract

Documenting the evolution and experiences of bioethics services contributes to a repository of successes and challenges that can serve as a lasting resource for all involved in bioethics work. This chronology of bioethics at The Hospital for Sick Children (SickKids) in Toronto, Canada, is one such documenting project. It describes events, challenges and successes that contributed to the Bioethics Department's evolution from an ethics committee to a department increasingly integrated into teams and processes across the organization. Using a mix of primary and secondary sources, including materials prepared for cyclical accreditation surveys, newspaper clippings, books and reports, meeting notes, eyewitness accounts, oral testimonies, video recordings, personal communications, and archival materials, we explore the development and integration of bioethics activities at SickKids and the ways in which staff and colleagues navigated the place and purpose of bioethics within the institution from the early 1980s to the present day. Each hospital-based bioethics resource reflects and contributes to the situated development of bioethics across local, national and international contexts. A focused examination of one department's development can preserve the contributions of people, practices, and contexts that defined major milestones in its development and shaped its organizational culture. Reflective work of this kind supports bioethics service development, ensures the lessons embedded in institutional knowledge remain accessible to current and future bioethicists, and contributes transferable insights that can inform other services and the broader field of applied bioethics.



ARTICLE (PEER-REVIEWED)

The Development of Bioethics at The Hospital for Sick Children: From Committee to Integration

Zoe Ritchie^a, Lucie Turner^b, James Anderson^{b,c,d}, Roxanne Kirsch^{b,e,f}, Maram Hassanein^{b,c,g}, Melissa McCradden^{h,i}, Lauren Chad^{b,e,j}, Sarah Lord^{b,e,k}, Randi Zlotnik Shaul^{b,c,e,g}

Résumé

Documenter l'évolution et les expériences des services de bioéthique contribue à constituer une base de données sur les réussites et les défis qui peut servir de ressource durable pour toutes les personnes impliquées dans le travail de bioéthique. Cette chronologie de la bioéthique à l'Hôpital pour enfants malades (SickKids) de Toronto, au Canada, est l'un de ces projets de documentation. Elle décrit les événements, les défis et les réussites qui ont contribué à l'évolution du département de bioéthique, qui est passé d'un comité d'éthique à un département de plus en plus intégré aux équipes et aux processus de l'ensemble de l'organisation. À partir d'une combinaison de sources primaires et secondaires, notamment des documents préparés pour des enquêtes d'accréditation cycliques, des coupures de journaux, des livres et des rapports, des notes de réunion, des témoignages directs, des témoignages oraux, des enregistrements vidéo, des communications personnelles et des documents d'archives, nous explorons le développement et l'intégration des activités de bioéthique à SickKids et la manière dont le personnel et les collègues ont abordé la place et l'objectif de la bioéthique au sein de l'institution depuis le début des années 1980 jusqu'à aujourd'hui. Chaque ressource de bioéthique hospitalière reflète et contribue au développement situé de la bioéthique dans des contextes locaux, nationaux et internationaux. Un examen approfondi du développement d'un service permet de préserver les contributions des personnes, des pratiques et des contextes qui ont marqué les étapes importantes de son développement et façonné sa culture organisationnelle. Ce type de travail de réflexion soutient le développement des services de bioéthique, garantit que les enseignements tirés des connaissances institutionnelles restent accessibles aux bioéthiciens actuels et futurs, et apporte des informations transférables qui peuvent éclairer d'autres services et le domaine plus large de la bioéthique appliquée.

Mots-clés

histoire, bioéthique pédiatrique, département de bioéthique, SickKids, Canada

Abstract

Documenting the evolution and experiences of bioethics services contributes to a repository of successes and challenges that can serve as a lasting resource for all involved in bioethics work. This chronology of bioethics at The Hospital for Sick Children (SickKids) in Toronto, Canada, is one such documenting project. It describes events, challenges and successes that contributed to the Bioethics Department's evolution from an ethics committee to a department increasingly integrated into teams and processes across the organization. Using a mix of primary and secondary sources, including materials prepared for cyclical accreditation surveys, newspaper clippings, books and reports, meeting notes, eyewitness accounts, oral testimonies, video recordings, personal communications, and archival materials, we explore the development and integration of bioethics activities at SickKids and the ways in which staff and colleagues navigated the place and purpose of bioethics within the institution from the early 1980s to the present day. Each hospital-based bioethics resource reflects and contributes to the situated development of bioethics across local, national and international contexts. A focused examination of one department's development can preserve the contributions of people, practices, and contexts that defined major milestones in its development and shaped its organizational culture. Reflective work of this kind supports bioethics service development, ensures the lessons embedded in institutional knowledge remain accessible to current and future bioethicists, and contributes transferable insights that can inform other services and the broader field of applied bioethics.

Keywords

history, paediatric bioethics, bioethics department, SickKids, Canada

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INTRODUCTION

Documenting the evolution and experiences of bioethics services contributes to a repository of successes and challenges that can serve as a resource for all involved in bioethics work. This chronology of bioethics at The Hospital for Sick Children (SickKids) in Toronto, Canada, is one such documenting project. It describes the events, challenges and successes that contributed to the department's evolution from an ethics committee to a department that is increasingly integrated into teams and processes across the organization.

The impetus of our project aligns with a characterization of bioethics articulated by scholars such as Onora O'Neill who describes it as "a meeting ground for several disciplines, discourses and organizations concerned with ethical, legal and social questions raised by advances in medicine, science and technology" (1). Among the many academic disciplines that inform bioethics, including philosophy, theology, law, medicine, nursing, social work, sociology, and anthropology, some scholars have articulated that one discipline remains conspicuously absent — history (2). While not a formal historical analysis, our project involves empirical and chronological narrative work¹. We sought to describe the evolution of bioethics at SickKids using a variety of primary and secondary sources, including materials prepared for cyclical accreditation surveys, newspaper clippings, books and reports, meeting notes, eyewitness accounts, oral testimonies, video recordings, personal communications, and archival materials. Some primary source materials consulted are privately housed within the Department of Bioethics, while others are publicly accessible through academic or hospital archives.

This paper is the product of a learning experience in collecting, synthesizing, and analyzing primary and secondary sources of importance to bioethics at SickKids and the field of paediatric bioethics. This work is primarily a reflection of written documents and oral testimonies that recount events and the individuals who contributed to bioethics work at SickKids. We sought to make reflexivity a priority in our process. The information uncovered was frequently discussed by the first and last authors and through the unique and essential lenses of the multiple authors. This paper does not serve as the comprehensive historical record² of the SickKids Bioethics Department or the field of Canadian paediatric bioethics ethics itself, but rather as a rich chronology informed by many primary sources that acknowledges its inherent limitations. This descriptive chronology leans into the department's unique dimensions and complexities. We acknowledge its challenging experiences alongside its positionality and contextual features of being situated in an internationally renowned paediatric research hospital, and specific contributions of department staff to engaging in the work of paediatric bioethics.

Each hospital-based bioethics resource, the Bioethics Department at SickKids being one example, reflects and contributes to the situated development of bioethics across local, national and international contexts. This paper shares the insights garnered from an accounting of the development and integration of its bioethics activities as its staff and colleagues navigated the place and purpose of bioethics within the institution, from the creation of a formal ethics committee in the early 1980s to the present day. A focused examination of one department's development can preserve the contributions of people, policies, and practices that defined major milestones in its development and shaped its organizational culture. Reflective work of this kind supports bioethics service development, ensures the lessons embedded in institutional knowledge remain accessible to current and future bioethicists, and contributes transferable insights that can inform other services and the broader field of applied bioethics³.

SICKKIDS: THEN AND NOW

The Hospital for Sick Children was founded in March of 1875 with the rental of an eleven-room two-story red-brick house on 31 Avenue Street that, by July of the following year, had treated 44 young patients (5). More than a century and a half later, The Hospital for Sick Children has evolved significantly. The 2024/2025 SickKids Annual Report reflects the scope of clinical care offered, reporting the average number of inpatient beds occupied daily at 293, emergency visits for the year totaling 62,964, and the hospital engaging in 12,241 operating room cases (6). In 2024/2025 the hospital staff, trainees, and volunteers totaled 15,119 (6). Supported by its academic affiliation with the University of Toronto, the hospital is competitive internationally for research intensity and output and is home to Canada's largest hospital-based child health research institute (7). The growing scope of the institution's activity over the years informed the rich range of ethical issues it faced. While its ethics supports were consistently resourced and engaged through the years, funding for bioethics staff and trainees were for the most part comparable with other Ontario bioethics services.

THE 1970s/1980s

The growth and institutionalization of bioethics at SickKids in the 1980s was informed by significant developments in the progression of the field of bioethics in the late 1970s. Several warrant brief reference in our exposition of the landscape in which discussions about bioethical issues took place at SickKids during this period. The Belmont Report was published in 1979 by the US National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (8,9) to

¹ The authorship team drew inspiration from Berg and Lune's (3) methodological guidance for historical research, which outlines a process for identifying sources and evaluating their relative authority or insight to advance the aims of the historical inquiry.

² We apologize for any omissions of individuals or projects that were genuine features of the work and evolution of Bioethics at SickKids. We would invite individuals to share these omissions with us should there be opportunities to include them in future iterations of this chronology.

³ Recent examples of this kind of reflective work in clinical ethics include: "1997: The Birth of ASBH in pictures and commentaries", a product of the American Society for Bioethics and Humanities (ASBH) History Project prepared by Loretta M. Kopelman (4) and made available publicly on the ASBH Website and "Moral Histories: Stories and Voices from the Founding Figures of Bioethics" a project of the Johns Hopkins Berman Institute of Bioethics that features interviews with founding figures of bioethics in the United States and Canada.

describe ethical principles that offer a foundation for the protection of vulnerable persons who participate in medical research. It has been suggested (10,11) that a historically overlooked task the Commission struggled with was how to apply the concept of autonomy to research involving children in a post-World War social landscape⁴. Ultimately, the committee landed on several essential guidelines for conducting research with child participants. These guidelines focused on the need for parental approval, the requirement to seek assent for children older than 7 years (10,11). These developments informed ethics integration with research at SickKids. The emergence of principlism also influenced the development of how the bioethics team approached clinical and research ethics consults in their early days, as well as the earliest iterations of its ethics frameworks. These important events were not only discussed but shaped the development of bioethics at the hospital.

As noted, the publication in 1978 of James Childress and Tom Beauchamp's first edition of *The Principles of Biomedical Ethics* gave rise to principlism as the predominant theory in applied ethics (10,12). Their theoretical framework for analyzing ethical issues in healthcare focused on respect for autonomy, nonmaleficence, beneficence, and justice (10). Beauchamp and Childress's Four Principles are now fundamental to current approaches to navigating ethical issues in healthcare (10,13). In the same year, Warren Reich published what is considered the first encyclopedia of bioethics — aptly titled the *Encyclopedia of Bioethics* — which formulated a widely accepted definition of bioethics as the interdisciplinary “systematic study of human conduct in the area of the life sciences and health care, insofar as this conduct is examined in the light of moral values and principles” (13). In addition, it articulated parameters for the scope of the field of bioethics as an academic discipline, provided one of the first systematized organizations of knowledge (in a Western context) of the field, and included a historical overview⁵ of its development (13,14). In reflections on his work many decades later, Reich offered insight into his observations that bioethicists in the 1970s systematically neglected most problems related to children, aside from issues of consent, which were a popular topic of discussion at the time (14). One reason for this neglect, Reich believed (14), was the highly restrictive conceptual framework of bioethics developed in the 1980s which made it difficult to effectively address or include the experiences of children. One of the distinct features of the Bioethics Department at SickKids was being conscious of this gap and committed to redressing it by contributing to the developing canon of paediatric bioethics.

The early ethics committee

SickKids was an early adopter of the formalized ethics committee model. Its inaugural ethics committee, established in the early 1980s, was first chaired by Geoff Barker, who was Director of the hospital's Paediatric Intensive Care Unit (PICU) (see Appendix 1 for the bioethics roles of individuals listed throughout this paper). Research conducted in 1984 found only 18% of hospitals in Canada had such committees (15). By 1989, ethics committees were established in 70 of 120 (58%) English-language hospitals in Canada with over 300 beds (16). Storch and colleagues have suggested this phenomenon can be linked to a Canadian Hospital Association policy statement (17) and a change in the Guide to Accreditation of Health Care Facilities in 1986 (18), which proposed that health care facilities might establish a multidisciplinary committee to address the need for policies on biomedical ethical subjects. While the policy statement was put forward as a recommendation, it is possible that healthcare administrators may have taken it as an accreditation standard (16), which in the context of a public healthcare system can necessitate quick organizational action. Similarly, in the United States, the 1992 Accreditation Manual for Hospitals Supplement from the Joint Commission on the Accreditation of Healthcare Organizations endorsed the use of committees for consideration of ethical issues arising from patient care (19). By the end of the 1980s, the “ethics by committee” model was the dominant approach to ethics consultation in healthcare institutions across North America (15,16).

In the 1980s, SickKids began a fruitful relationship with scholars at the Westminster Institute for Ethics and Human Values, which had been established in 1978 in London, Ontario (20). The Director of the Westminster Institute, Abbyann Lynch, joined SickKids in 1986 as a consultant bioethicist and served on the newly formed ethics committee. The Committee's broad membership consisted of approximately 20 individuals drawn from diverse backgrounds, including medicine, law, social work, nursing, patient representatives, and hospital board members. In 1983, Jonathan Hellmann of the Division of Neonatology was appointed Committee Chair. Lynch was doing bioethics consultations from her first interactions at SickKids, mobilizing the ethics committee when she determined a consult would be aided by the diversity of their collective expertise and experiences. At full committee meetings, Lynch would briefly describe the clinical consultations she led, accounting for the issues about which she was being consulted. Together Lynch and Hellmann, sought to focus the efforts of the committee on establishing a standardized process for ethics consultation by ethicists and the enhancement of ethics education and ethically-informed policy development within the institution.

The merits of consultations by full committee versus the use of a single consultant bioethics model continued to be debated among healthcare organizations into the 1980s and 1990s. Some of the defenders of the ethics by committee model believed that consultation by an institutionally approved group sent an admirable message that ethics ought to be practiced in community, for the benefit of the community (21). On the other side of the debate, some organizations were choosing a single consultant bioethics model which allowed ethics consultations to be more flexible, performed as they were by a sole ethicist who could then engage with a committee when appropriate (22). Disagreement also existed about whether ethics committee compositions appropriately distinguished individuals with an interest in ethics from those with specific training and expertise in

⁴ The Commission's deliberations took place during the post-World War II period of rapid change in the understanding of childhood and adolescence, brought on in part by school children's roles assuming risks in the polio vaccine trials, and the civil rights movement and evolving legal precedents that gave them additional safeguards in treatment access and research participation (11).

⁵ The Encyclopedia also included a comprehensive history of the discipline — one of the credited contributors to this section, Abbyann Lynch, then an Associate Professor of Philosophy at St. Michael's College, University of Toronto, would become one of the foremost leaders in paediatric bioethics ethics at SickKids, as well as within the Canadian and International communities.

the discipline. General thinking at the time was that ethics committees should be constituted to ensure diverse representation of professional, cultural, political and social biases, as well as diverse values and belief systems (22). On this view, the strength of the committee's ethical expertise was not understood as being at an individual level but rather at a collective one. A committee's ability to navigate ethical issues would thus be enriched by the diversity of experiences and thought within the committee membership.

Over time, SickKids adopted a single consultant bioethics model which became a wide-spread norm for bioethics consultation in Canada and beyond. Within the ethics committee, a subgroup was formed which developed a consultation process open to anyone at the hospital. Committee members were supportive of moving forward with the model of consultation by bioethicists, even though it was different from the model of consultation predominantly used across North America at the time⁶. The committee was initially concerned about how medical staff would react if anyone on their team could request an ethics consult. They brainstormed about how to ensure that all hospital staff would be aware of this model and empowered to avail themselves of this bioethics service. It took time to disseminate the model and rationale, but it eventually became well accepted. In addition to patients and families, any staff member or trainee could request a consult without declaring their intention or seeking permission. The bioethicist would work out with the requestor who else should be involved with discussions. We understand that hospital staff found bioethicists Lynch and Baylis to be trustworthy and discreet.

Similar to many such services across Canada, at SickKids bioethics services worked with a range of documentation modalities in an attempt to capture the quantities and qualities of ethics consultations. At different stages documentation has included identifiable information, broad definitions of what constitutes a consultation, and narrower definitions. Over the years, bioethics consultation evolved to being available to any patient, substitute decision maker, staff, trainee or volunteer with an ethical issue linked to their experience at SickKids.

Child rights

To appreciate the landscape in which discussions of child rights would be taking place at SickKids, it is important to examine the 1989 adoption of the United Nations Convention on the Rights of the Child (UNCRC) by the United Nations General Assembly, an event that would shape the zeitgeist of human rights and bioethics (26). One of the first comprehensive articulations of children's rights in international law, the UNCRC had significant implications for how rights and interests of children were understood in healthcare settings. Specifically, the UNCRC charged member states with ensuring that basic survival requirements were met for all children, including food, clean water, and health care and strongly stipulated that children should be afforded rights of protection against neglect and exploitation. Crucially, the UNCRC emphasized that children have a universal right to education, access to information, and to express their views in all matters affecting themselves — with their views being given due weight in accordance with their age and maturity, in member states responsible for protecting and promoting these rights (27). The Convention was effective in entrenching, in the canon of children's human rights law, the importance of the parent-child relationship, children's positive right to protection and children being individuals in their own right rather than merely extensions of their parents (28). Underscored by the departmental documents reviewed for this project, these concepts would go on to be of enduring relevance to the care of children at SickKids, the work of Pro Bono Law Ontario at SickKids, and to cases where bioethics services were engaged.

The inclusion of the concept of the best interests of the child⁷ as a guiding principle for all articles in the Convention was similar to the use of this concept in judicial cases across North America. Legal decisions addressing ethically complex issues in paediatrics and scholarship in paediatric bioethics have a long bi-directional relationship where each frequently informs the reasoning of the other. Cases which did so in the 1980s (and early 1990s) asked courts to weigh in on the rights of persons with mental disabilities to be protected from sterilization⁸, the responsibilities of parents as substitute decision-makers⁹, the interests of children in receiving religious instruction¹⁰, and the substantive legal content of best interests as a guiding principle¹¹. Bioethics services at SickKids have always worked in collaborative relationships with health lawyers and health law

⁶ It should be noted the context for the development of ethics committees within healthcare institutions in the United States was influenced by concerns regarding the legal liability of physicians in cases where there existed significant ethical questions regarding the permissibility of withdrawing life sustaining care (23). A notable legal case which took up these questions was that of Karen Anne Quinlan, in 1976, and occurred at a time when ethics committees were becoming more widespread (24); the issue has been revisited in several other cases in the US, including, notably, that of Nancy Cruzan in 1990 (25).

⁷ The best interests of the child is generally expressed as a principle or standard in Canadian law and bioethics. The principle is considered a substantive right and guiding principle that covers all rights laid out in the UNCRC. Examples of express references to the best interests of the child in federal law adopted in the 1980s include the Divorce Act, 1985 (29), and the Citizenship Act, 1985 (30).

⁸ Both the best interests standard and the *parens patriae* doctrine were discussed at the 1986 Supreme Court of Canada (SCC) in *E. (Mrs.) v. Eve* (31) regarding a mother's consent to the sterilization of her adult daughter who had disabilities. While this controversial case concerned substitute decision-making on behalf of an adult, it set a precedent that would influence the application of the *parens patriae* doctrine and best interests standard to future SCC cases on the rights of children.

⁹ In 1983, guardians of an infant in New York born with significant disabilities challenged the legal theory behind a set of federal rules implemented in the early 1970s, that nontreatment for infants born with disabilities was discriminatory and an infringement on the civil rights of said infants. The case went to the US Supreme Court, which ruled these rules as unnecessary to protect the rights of infants with disabilities and as interfering with parental rights to consent or refuse treatment based on what they deemed to be in their infants' best interests (32). In response, the US Congress adopted an updated set of guidelines. As some scholars have pointed out, while distinct, both sets of rules are often associated and referred to as "The Baby Doe regulations." There has been vigorous academic debate on the inconsistency of these rules, presently, with the best interests of the child principle, individualized decision-making, and quality of life concerns (33-35).

¹⁰ This issue was discussed in *Young v. Young* heard before the Supreme Court of Canada in 1993 (35). The court considered the best interests of children to be a child-centric analysis that should not strictly focus on the absence of harm.

¹¹ Several North American legal cases in the 1980s began to use and debate the substantive legal content of the best interests principle. For cases heard at the Supreme Court of Canada, see (31,36-44).

professors within and outside the organization, including hosting many Bioethics Grand Rounds where legal experts presented on a new piece of legislation or new legal decision that had an ethical dimension relevant to paediatrics.

The 1980s was a significant time for both the translation of legal and ethical thought into the rights and treatment of children in healthcare settings, and reflections on how the work of ethics consultants and committees in hospitals ought to meet the pressing challenges before them. The SickKids model had ethics consultations and adjacent activities led by experienced bioethicists with explicit background in philosophy and applied ethics. This model set the tone for the creation of a Department of Bioethics at SickKids in 1991.

THE 1990s

Founding the “Department of Bioethics”

SickKids founded its Department of Bioethics in 1991, embracing the recommendation of the ethics committee established almost a decade earlier. Abbyann Lynch was appointed Director and her prior colleague at the Westminster Institute, Françoise Baylis, joined the department as its first bioethicist. The bioethicist lineage that followed in the subsequent decade included Christine Harrison, Mary Rowell, Mona Sidarous, and Louis Charland in a part-time capacity. Research activities were supported by Louis Kunicki and several student volunteers and research assistants. The Bioethics Committee remained operational until 1993/4 when it was renamed the Bioethics Advisory Committee.

The Department was introduced to the wider hospital in the Department’s inaugural newsletter, *Calyx: Ethical Issues in Paediatrics*, which was also established the same year,

We look forward to working with others involved in the care of paediatric patients, and the study of ethical issues, hoping thereby to increase the awareness of staff and parents concerning ethical issues relating to the provision of health care to infants, children and youths (45).

Despite much enthusiasm for the announcement, not everyone in the institution responded positively. The presence of the new Department highlighted an underlying critique of bioethicists whose role was (anecdotally) misconceived by some as policing from a perceived moral “high ground.” It is said that on the first day of the Bioethics Department’s establishment, a sign was posted on a wall just outside a SickKids operating room saying, “The Ethics Police Have Arrived.” This prompted recognition of the need to build relationships with different departments to integrate more closely with the wider multi-disciplinary teams and facilitate collaborations. The Department bioethicists throughout the decade would realize acceptance of their role. This was influenced, at least in part, by their efforts to navigate the unique practice cultures of different clinical departments in the hospital. Each subculture had a strong influence on the receptiveness of its members to ethics support offered by the Department. It would take time to understand the bureaucratic structures, individual personalities, and team dynamics, and this influenced the approaches taken by Lynch, Baylis, and later Harrison, Rowell, and Sidarous, to build a collaborative ethics program. As Director, Lynch led and contributed candidly to conversations occurring across Canadian healthcare institutions on the challenges of providing collaborative ethics support (46).

In 1991, the Bioethics Committee developed and published institutional guidelines for bioethics consultations (46). The guidelines highlighted the purpose and process for ethics consultations and represented a significant shift towards acknowledging and standardizing the role of bioethics consultations within the institution. The Department activities evolved throughout the decade and were ultimately organized under four pillars of activity across clinical, educational, and scholarly domains. They were, and continue, to include:

1. Ethics Consultation — seeks to identify, analyze and support the management of ethical issues.
2. Policy Development — seeks to support the management of ethical issues through policy and guideline development at an organizational level.
3. Education on Ethics and Ethics in Education — seeks to deliver ethics education, and to identify ethical issues in the provision of education across the hospital.
4. Research on Ethics and Ethics in Research — seeks to conduct bioethics research, bioethics scholarship and ethical review of research conducted by hospital staff and with hospital patients.

Tracking ethics consultations

Ethics consultations have consistently been a priority of bioethics services at SickKids, from the inauguration of the Department. Pervasive questions at SickKids, which continue to parallel broader debates in the profession (48-56) related to tracking consultations, included whether markers of quality would be consultation numbers increasing over time (indicating requestor satisfaction or limited learning) or reducing (indicating learning that could be applied in future cases or perceived limited utility). In its early years, tracking was conducted in paper form: each consult had a file, collation was done for Departmental priority setting and annual reporting and printed in a paper-bound bi-annual report. Records of this period with regards to ethics consults numbers were shredded during the hospital’s move away from “shadow charts”, recognizing the need to have all relevant consultant materials in the single patient chart. Due to these limitations, and despite our best efforts,

we are unable to meaningfully compare data sets for clinical consultation across the development of the Department. We return below to how, in the 2000s, data collection methods on tracking ethics consultations evolved as a priority for the Department.

Creating spaces for paediatric bioethics discourse

The Department had a consistent commitment to creating spaces to engage in multiple forms of ethics discourse. Department members have always supervised and mentored trainees in graduate programs, electives, fellowships and even volunteer opportunities. Members have taught formal courses through the University of Toronto and provide all forms of didactic and discourse education across the hospital. In conjunction with efforts to engage in education, the dissemination of scholarly work through publication emerged as a distinct priority for the Department during the 1990s. An oddity for a hospital at the time, SickKids ran an in-house publishing press which enabled the Department to produce several significant publications. Baylis led the development of several books published by the Department during the 1990s. The 1993 publication of *Paediatric Ethics in a Canadian Context* (57) and 1994 publication of *Institutional Policy in Paediatric Practice: Documenting Canadian Experience* (58) offer unique windows into the evolution of Canadian paediatric clinical ethics, and the latter which includes the then terms of reference for hospitals ethics committees across Canada. Similarly, *Codes of Ethics*, published first in 1992 (59), and then reedited in 1999 (60), detail the ethics and professional practices codes of many health disciplines and allied health professions during this period. From the additions and exclusions across both editions, it is possible to discern tonal shifts in the values prioritized by institutions over the decade. These books were well received, and often due to high demand, received second prints.

As part of its focus on producing high quality written work, the Department newsletter, “Calyx”, launched in 1991, became a popular publication within the hospital and continued to be published into the early 2000s. Many contributors to Calyx, including scholars, clinicians, and students worldwide, would go on to have careers in clinical and academic bioethics across North America. In searching through department documents for informative materials, we unexpectedly found an international mailing list which documented the broad reach of the newsletter (61). The thoughtful debate and dialogue in the pages of Calyx found its way into the hands of scholars, healthcare professionals, and bioethicists in Canada, the United States, Australia, China, Columbia, England, Israel, Russia, and Trinidad, among others. Notably, many core topics discussed in Calyx articles from the 1990s (62-67) — including determinations of best interests, the capacity of children to participate in clinical and research decision-making, and ethical distinctions between consent and assent — remain salient ethical issues in paediatric healthcare institutions today.

Departmental collaborations and communities of practice

Acknowledging the significance of ethical issues to paediatric clinical practice and decision-making, in 1991 the Bioethics Department launched the “Everyday Ethics” bioethics discussion series, which had wide participation from multiple clinical departments and often featured collaborative presentations between ethicists and healthcare providers¹². The popularity of the series drew attention from other hospitals in the Toronto area and collaborations with those hospitals were facilitated through video conferencing, which would grow more reliable as the decade progressed. While collaboration was a priority for the team, being a standalone department also had its own distinct benefits; notably, it granted the Department significant agency over its activities and hiring practices while enhancing institutional engagement through active participation in decision-making committees. During this time, the Department championed numerous initiatives, including educational activities for staff and trainees, and broadening access of the ethics consult service to staff, parents, patients, trainees, and volunteers, thus allowing direct access to a bioethicist.

At the start of the 1990s, several bioethics departments within Toronto’s academic hospitals, including SickKids, were navigating their relationship with their common academic partner, the University of Toronto. In personal communications among department bioethicists, these hospitals were often collectively referred to as “The University Avenue hospitals,” reflecting their proximity on this downtown street. While the ethics committees and departments at the University Avenue hospitals had a record of collaboration, talks began with the University of Toronto to establish a more solidified partnership. Lynch had long been an ardent advocate for the development of a large-scale paediatric focused bioethics centre. However, after extensive discussions between SickKids and the University of Toronto about various models for bioethics collaboration, she would be disappointed as a different approach was ultimately adopted.

In 1995, SickKids, in collaboration with Sunnybrook Hospital, Mount Sinai Hospital, Toronto General Hospital, and the University of Toronto founded the University of Toronto Joint Centre for Bioethics, often known by its shortened moniker “The JCB” (62). The JCB marked a significant departure from traditional models of bioethics centres based either in universities or in healthcare institutions. Designed collaboratively in an attempt to bridge the gap between bioethics theory and practice, the centre sought to both advance bioethical thinking and enhance clinical ethics practices in healthcare (62). The JCB continues to maintain a strong relationship with the Bioethics Department at SickKids. Nevertheless, concerns that involvement with the JCB — given its broad range of focus areas — might overshadow the specific needs of paediatric bioethics remained

¹² The Bioethics Department maintains a record (68) of all the sessions that occurred in the series. A few notable examples include: “*Family Secrets: Preserving Confidentiality in the Practice of Genetic Counseling*” co-presented by J. Siegal (Genetics) and A. Lynch (Bioethics) in 1994; “*The Doctor will be with you in just a moment but not in person, the ethics of telemedicine*” co-presented by J. Cooper (Surgery), A. Paven (Telemedicine) and M. Rowell (Bioethics) in 1995; C. Harrison and C. Sass-Kortas in 1996 “*Better or Worse? Proposed Changes to Ontario’s Consent Law*”; and F. Baylis and A. Goldbloom (Bioethics/Law) in 1992 “*Ontario’s proposed consent to treatment legislation: you, your patients, and their rights advisors.*”

relevant throughout its history. SickKids bioethicists have advocated for strong paediatric ethics representation and education within the JCB, since its founding¹³.

Also in 1995, the Royal College of Physicians of Canada issued a call to bolster bioethics education¹⁴ among Canadian medical residents. Members of the SickKids Bioethics Department¹⁵ collaborated with the Paediatric Ethics Network (PedEthNet) to create a first of its kind medical ethics curriculum for use in paediatric residency programs. The comprehensive curriculum, “The Good Paediatrician: An Ethics Curriculum”, was published in 1996 (69). Despite the intention of its authors, the curriculum was never formally adopted by Canadian medical schools. In speaking with individuals who worked on the project, we learned that the team lacked sufficient support to demonstrate the value of the material to the interest groups responsible for curriculum design, monitoring, and decision-making in Canadian medical schools. While today the Government of Canada Tri-Agency funding programs emphasize and support robust knowledge mobilization plans, this is a relatively new development. If the anecdotal reports are correct, they underscore a pervasive issue in the funding of bioethics-oriented research projects — that regardless of the quality of the work produced, if insufficient support exists to engage interest groups and decision-makers the true value of this work remains unrealized.

Lynch’s championing of paediatric bioethics was continued by her successor, Christine Harrison, who took up the position of Department Director following the end of Lynch’s¹⁶ tenure in the mid 1990s. Harrison created the Canadian Paediatric Bioethics Network (CPBN) to offer opportunities for bioethicists working with children and families to have collaborative dialogue with one another. The number of paediatric bioethicists was and continues to be relatively small in Canada. The CPBN offered a novel opportunity for an organized community of practice for colleagues working across broad geography and different provincial healthcare systems. Today, the Canadian Bioethics Society (CBS) supports several interest groups¹⁷, but the CPBN, today recognized as the Canadian Paediatric Bioethics Interest Group, got its start in the mid 1990s¹⁸. In its earliest iterations the CPBN would connect via a telephone conference call several times a year and hosted an in-person group meeting at the annual Canadian Bioethics Society conference. The CPBN gained prominence over the decade hosting a popular pre-conference ahead of the annual CBS conference which for eight years¹⁹ running (up until the COVID-19 pandemic). These paediatric bioethics pre-conferences were a unique feature for a general bioethics conference as they isolated explicit space for the conference theme to be examined through the lens of paediatric bioethics.

Engaging on issues of consent, capacity, and substitute decision-making

In the early 1990s, the Government of Ontario recognized the need to address healthcare consent issues comprehensively, particularly after concerns were raised regarding patient rights, the role of substitute decision-makers, and legal standards around consent. In 1992, Ontario introduced legislation specific to healthcare treatment decisions — the Ontario Consent to Treatment Act (72). This Act formalized the common law principle that decision-making ability is based on capacity rather than age; in Ontario there would be no age of consent for treatment. During this time, the Bioethics Department hosted several Everyday Ethics sessions on the impact of the legislation at SickKids, including a 1992 Everyday Ethics session hosted by Baylis and Goldbloom (73). Bioethicists at SickKids proposed recommendations to The Ministry of Health concerning these legislative changes that would be consequential to the creation of the Ontario Health Care Consent Act (HCCA) which came into effect in 1996 (74). The HCCA remains the Ontario law that governs the ability of persons (regardless of age) to consent to healthcare treatments and admission to care facilities.

Reflecting provincial efforts to address healthcare consent issues, bioethicists at SickKids were engaged in a myriad of complex discussions regarding consent during this time. A particularly challenging question centred on how much responsibility lies with a hospital to contact former patients if new information suggests that they may have sustained unforeseen harm during treatment. Prior to 1985, Canada did not have a comprehensive testing program for the transmission of blood-borne viruses, like HIV, HBV, or HVC, built into its voluntary blood donation system (75). In what is considered a significant public health failure, a great number of Canadians received blood products contaminated with HIV and Hepatitis C. The Government of Canada would overhaul the governance of the domestic blood supply following the “Krever Report” in 1997 (75). The Report directed hospitals to undertake reviews of their records in order to identify former patients who received blood and blood

¹³ They have contributed to the education and training of over 400 students and fellows who participate in graduate programs, bioethics electives, and clinical ethics fellowships hosted at the JCB

¹⁴ Broadly, the objectives were to integrate bioethics skills and knowledge into the clinical practice of residents in accredited programs, to assist postgraduate specialty and subspecialty programs in teaching bioethics to their residents, to develop model curricula for use within these programs, and to develop methods to evaluate the bioethics knowledge, skills, and attitudes of residents.

¹⁵ Then SickKids staff members affiliated with the project included Abbyann Lynch (bioethics), Francoise Baylis (bioethics), Christine Harrison (bioethics), Jonathan Hellmann (neonatology), Robert Hillard (paediatrics), Mary Rowell (bioethics), Susan Tallett (medical education).

¹⁶ Abbyann Lynch is remembered, following her passing in 2019, as a distinguished philosopher, bioethicist, mentor, and fierce advocate for the rights of children. She was a founder of the Canadian Bioethics Society and a charter member of the National Council in Bioethics in Human Research. In her lifetime she received multiple prestigious honours, including induction into the Order of Ontario (1993) and the Order of Canada (1997) (70).

¹⁷ In an effort to support the role of the Canadian Bioethics Society and benefit from its engagement efforts across Canada, in 2025, the CPBN evolved into the Canadian Paediatric Bioethics Interest Group. As of August 2025, additional interest groups include: Indigenous Ethics, Rural and Remote Ethics, Ethics in Nursing, Environmental Ethics, Religion and Bioethics, MAiD and Bioethics, Disability Ethics, Practising Healthcare Ethicists, Artificial Intelligence and Healthcare Ethics, Global Bioethics, Moral Distress, and Mental Health and Substance Use Health (71).

¹⁸ According to the information we were able to obtain, the CPBN was founded in the mid-1990s as ethicists, including Harrison, organically moved existing regular conversations and collaborations into a more formal network with recurring meetings, collaborative mentorship, and information sharing.

¹⁹ This important streak ended when the COVID-19 pandemic put a stop to in-person events. However, the CPBN is still active, and at the latest Canadian Bioethics Conference (co-hosted with the International Conference on Clinical Ethics and Consultation) in Montreal (Spring 2024), the CPBN held an afternoon meeting with 60+ members in attendance.

products between 1978 and the end of 1985, and where such records were still in existence, to directly notify these patients to inform them about the risks of HIV infection and provide counselling about the advisability and availability of HIV testing.

Aside from the contributions the Department made to the creation of the HCCA, by the end of the decade, Everyday Ethics sessions also made space to discuss central issues such as what it means to navigate decision-making in the context of participatory rights, emerging autonomy of young people and bioethics principles such as best interests of the child²⁰. Several influential decisions²¹ at the Supreme Court of Canada (SCC) on questions regarding the rights of children and the value of the family structure demonstrate that these issues were, and continue to be, important to Canadians.

THE 2000s

Under the continued leadership of Harrison, the early 2000s marked a period of change within the Bioethics Department (see Appendix 2 for diagram of the Department's structure as of 2025). In 2001, Randi Zlotnik Shaul was hired as a bioethicist and became an active member of the Research Ethics Board at SickKids, building on the engagement of Lynch, Baylis, and Rowell in contributing to research ethics education and ethics oversight of hospital-wide research activities.

Reporting relationships and academic linkages

This new decade also ushered in changes in the Department's reporting relationship to the hospital's senior administrative team. The reporting relationship of an ethics service affects its activities and capabilities and is an under-discussed topic in organizational ethics²². Oral accounts indicated that in 1991, the Department first reported to the Executive Vice President and Chief Operating Officer, Alan Goldbloom, then later to the VP of Medical and Academic Affairs, Ronald Laxer, strengthening their relationship with physician groups within the hospital. In the early 2000s, the Department began reporting to the Chief of Nursing and Interprofessional Practice, Margaret Keatings, which presented a new opportunity to bolster engagement with interprofessional groups within the hospital. Pam Hubley followed Keatings in her role as Chief of Nursing and Interprofessional Practice. When Hubley's portfolio later expanded as she became VP of the SickKids Learning Institute and International Nursing, bioethics remained in her portfolio. The Department is currently benefitting from interprofessional relationships built over time as well as integration within medical teams facilitated by reporting to Lennox Huang, CMO and VP Medical and Academic Affairs. Similar to any bioethics service embedded within a large organization, the ability to provide support and have an impact is tightly linked to reporting relationships and the support garnered from executive leaders. Each period of the Bioethics Department's development is characterized by distinct institutional opportunities and challenges manifested by leadership support, available funds, and collaboration across hospital committees.

Impact and quality in academic health sciences centres are often recognized through academic designations. Consistent with their long-standing commitment to academic contribution and integration, departmental bioethicists have been supported in seeking academic appointments at the University of Toronto, fulfilling reporting and promotional requirements in the departments of Paediatrics, Family Medicine, the Institute for Health Policy, Management and Evaluation and the Dalla Lana School of Public Health; additional appointments were made in the School of Graduate Studies at the University of Toronto and, where pertinent other universities, to facilitate membership on graduate student thesis supervision committees. Given the relatively small number of non-physician hospital-based bioethicists that move forward for promotion in these university departments, each stage of the promotion pathway was somewhat novel for both the bioethics candidates and their reviewers in these departments²³.

Ethics engagement within and outside of SickKids

It was during this era that the Department adapted some of its educational activities to meet the evolving needs of the hospital. Everyday Ethics was rebranded "Bioethics Grand Rounds" to fit more comfortably into established language within the educational infrastructure of medical departments at SickKids. The Bioethics Grand Rounds²⁴ were not necessarily a new offering in terms of content or structure, but the new branding signposted to clinicians that the Department understood their educational culture and were crafting opportunities to engage in moral discussion with clinicians in a more familiar, and incentivized format (the Department sought and maintains a qualification to provide CME²⁵ credits). Given their popularity, several Bioethics Grand Rounds have become annual offerings. The "Bioethics Book Review" for example, discusses a pre-selected novel that engages with ethical health-related issues affecting young people, while the "Bioethics Year in Review" highlights key paediatric ethics issues that have made media headlines during the year.

²⁰ Everyday Ethics sessions hosted by the Department between 1995-99 discussed: the ethics of surgical sterilization of children with profound disability — "*Whose Needs are Being Met?*" (76); a child's right to refuse treatment — "*When Does No Mean No?*" (77); respectful involvement of children in research — "*Yes They CAN Understand!*" (78); and best interests in the use of alternative treatments — "*Who Decides What's Best?*" (79), among many others.

²¹ The decision made in *Young v. Young* (36) situated the best interests of the child as child-centric analysis that should not focus strictly on harms. In 1999, *Baker v. Canada (Minister of Citizenship and Immigration)* (80), a significant administrative law decision of the Supreme Court of Canada, among other issues referred to the UNCRC in their analysis. In *Gordon v. Goertz* (81), the court considered the interests of children with a child-centric analysis.

²² This relationship affects the type of issues they are informed of by senior leadership, the mechanisms by which the Department reports yearly activities, and which senior leaders are most up-to-date with bioethics activities throughout the hospital.

²³ Harrison, Zlotnik Shaul and Greenberg were promoted to Associate Professor in the Department of Paediatrics at the University of Toronto; in 2024, Zlotnik Shaul became a full professor in the Department of Paediatrics.

²⁴ Bioethics Grand Rounds at SickKids include a variety of formats throughout the annual series, with some focused on a clinical case, others on a broader conceptual issue with interdisciplinary dimensions, and a couple of specialty rounds including an annual year-in-review and book review.

²⁵ Continuing Medical Education credits.

In 2001, Bioethics Week was established, providing the opportunity for clinical teams and departments across the institution to host open events discussing ethical issues relevant to their context. The structure of Bioethics Week, conceptualized by Harrison, encourages each division or team to use their regular academic rounds or equivalent to focus on an ethics topic pursuant to their service. Individual services take the lead in selecting the topic, with the Bioethics Department supporting them with speaker selection and format if needed. During this innovative week, events are open to staff, trainees, and families to explore ethical issues in both new and familiar clinical areas and disciplines²⁶. The week has become a key platform for discussing contemporary and longstanding ethical issues²⁷. While in 2024, Bioethics Week held twenty-plus events with over one thousand attendees, the first Bioethics Week marked a humble (yet ambitious) beginning for the tradition, engaging in eight well-attended events. Notwithstanding the fact that the Department is situated within an organization with a large annual budget, the funds dedicated to the Bioethics Department have consistently called for careful allocation, aiming to be as effective as possible while managing hospital-wide budget cuts that led to the loss of Department staff and resources. Bioethics Week was a creative way to host a hospital-wide annual event without the need for much draw on the Department budget.

Accreditation Canada has priority standards about principle-based decision-making that call upon hospitals to have resources to recognize and support the identification, analysis and addressing of ethical issues. These resources together constitute the hospital's "Ethics Framework" and include the Bioethics Department and its services. The Bioethics Department engages in ongoing hospital-wide education and dissemination about the Ethics Framework.

With all this success, and evolving collaborations, we would be remiss to not also acknowledge the 1990s as a period where numerous passionate discussions occurred between bioethicists, at SickKids and beyond, regarding their responsibilities as members of a growing "non-professional-profession". One notable illustration of these debates emerged in the context of the Olivieri Affair, a controversy that later gave rise to a published exchange between two SickKids bioethicists.

Ethical controversy discussed publicly — the "Olivieri affair"

In 2004, The Journal of Medical Ethics featured a seminal exchange between two SickKids bioethicists, Baylis and Rowell, the latter who had been a bioethicist at SickKids during what became widely referred to as the "Olivieri affair"²⁸, and which was the catalyst for their exchange. In Baylis' initial commentary to the journal, aptly named "Where were the heroes of bioethics?" (86), she argued that the wider bioethics community had failed to play a pivotal role:

Bioethicists in Canada failed Dr Olivieri and her colleagues at HSC. Why? Did they fear losing their jobs? There are few bioethicists who have the security of tenure. Did they fear being sued? Many of the individuals and organisations involved in this case had shown themselves willing to engage in litigation. Did they fear loss of reputation? Again, many involved in this case had shown themselves willing to make damaging public comments. Did they fear retribution and consequent damage to their careers? After all, bioethics in Canada is a very small and fractured community. I do not know the reason(s) for the ensuing silence. I do know, however, that by and large Canadian bioethicists failed to speak up when there was ample time and opportunity. As a responsible community, we must ask ourselves whether we could and should have done more (p.49).

In her reply (87), Rowell sought to contextualize the facts she believed were not accurately represented in Baylis's piece, and to clarify her role in the case. She stated that:

My efforts to support Dr. Olivieri were often dismissed by the hospital administration and sometimes also by the media, who were perhaps seeking a more sensational account of the case than I felt it appropriate to provide, believing such an approach to be contrary to the best interests of children in research and contrary to support of Dr. Olivieri and her colleagues (p.50).

Baylis's response to Rowell (88) drew international attention to what she believed was an important lesson for the wider bioethics community to glean from the incident:

²⁶ Some of the activities included in Bioethics Week are a named lecture in memory of Christine Harrison, former Director of the Bioethics Department, and an academic poster display, where staff and trainees from across the hospital can showcase their bioethics-relevant work with an award named for the inaugural and current clinical bioethics associate, Jonathan Hellmann.

²⁷ These have included ethical dimensions of treating 2SLGBTQIA+ individuals and families following Canada's legalization of same sex marriage in 2005 under the Civil Marriage Act, the implications of truth-telling and confidentiality in paediatric care with the hospital's growing reliance on electronic records, and the extent to which paediatric care should be prioritized in society. Frequently, the ramifications of legal decisions, like *A.C. v. Manitoba* (Director of Children and Family Services), a landmark Supreme Court of Canada case adjudicated in 2009 on the rights of "mature minors", became fervent points of discussion (82).

²⁸ The "Olivieri Affair" was named after Nancy Olivieri (BSc, MD), who was the former head of the hemoglobinopathy program at SickKids. She was embroiled in a four-year legal battle involving SickKids, the University of Toronto, and Apotex Inc, a Toronto-based pharmaceutical company. In 1996, she broke the confidentiality agreement which governed her research sponsored by Apotex to share with patients and the wider scientific community her serious concerns that her findings demonstrated the potential dangers of using deferiprone to treat children with thalassemia. Apotex pulled its funding from the University, for which it was negotiating a \$30 million dollar donation, and pursued legal action against Olivieri; she was then removed from her post at SickKids, though she would later be reinstated. Thorough accounts of the affair have since been published (83-85). A report published in 2001 into the affair commissioned by the Canadian Association of University Teachers (CAUT) exonerated Olivieri of any wrongdoing (84). The Olivieri Affair raised issues of research ethics and academic freedom that were illustrative of the growing pressure in the mid-1990s for universities, teaching hospitals and individual researchers to seek corporate sponsorship for projects (84). As the CAUT report detailed, public institutions were not conscious of the inadequacy of their policy infrastructures for protecting the public interest in this new environment, and policies and practices had not been changed to consider these new circumstances.

The lesson for all of us in this is that speaking truth to power — the job of bioethics — is a daunting task and one that we are unlikely to succeed at if we do not learn to ask for and to accept, to offer and to provide, moral support and meaningful help (p.52).

This exchange offers a touchpoint to an ongoing existential debate in the profession that, we contend, goes much further back than the 1990s. This debate asks the community of practice to consider the purpose of a bioethicist, and further, what moral duties that purpose conveys. Is it possible for a bioethicist to serve institutions, individuals, and communities, particularly when the interests of these parties can be significantly at odds? These questions, which remain significant at SickKids and not without disagreement among bioethicists in Canada, are further complicated by increasing calls for the professionalization of clinical ethicists (89-91) and growing critique of the lack of intellectual and cultural diversity among North American bioethicists (92,94).

THE 2010s TO 2025

Between 2010 and 2025, the Department welcomed many new faces, and several novel roles reflective of a desire to create a team that increased complementary interdisciplinarity in academic and professional backgrounds. After being replaced through the structure of a Department, a Bioethics Advisory Committee was reinstated in 2017 to support the Bioethics Department and to serve as a forum for bringing multiple disciplinary lenses and vantage points to deliberations about challenging ethical issues facing the organization, as well as ethics capacity building for members as “ethics ambassadors”. Prior to Zlotnik Shaul being hired as the Director of the Department, a needs-assessment was conducted by two external experts in paediatric bioethics (one from Canada and one from the United States). They recommended that the work of the small department could benefit from the assistance of a Bioethics Advisory Committee. This new iteration of the committee is interdisciplinary, with at least 20 members representing roles across the institution. The inaugural co-chairs were critical care intensivist Peter Cox and Zlotnik Shaul; when Cox retired from SickKids, staff physician Kevin Weingarten took over as co-chair.

With respect to bioethicist roles, at the start of the 2010s, bioethicist Rebecca Greenberg (with a background in nursing and bioethics) joined the staff and Zlotnik Shaul followed Harrison as Director. Bioethicist Alison Williams joined for a one-year contract, bringing increased attention to ethical issues within hospital roles such as maintenance and environmental services, often overlooked in traditional bioethics services. Bioethicists within the Department have come from diverse disciplines — most commonly philosophy, but also law, health policy, spiritual care, nursing, neuroscience, pharmacy, and novel therapeutics²⁹. A consistent feature of the team at SickKids has been the inclusion of a member with extensive philosophical training, offering a distinctive depth and critical perspective to the team. This sentiment was reaffirmed when bioethicist James Anderson joined in 2013. Anderson’s work at the intersection of ethics and epistemology would prove invaluable as the hospital’s strategic focus shifted to precision child health and the integration of artificial intelligence into clinical care. The addition of Melissa McCradden, completing the first fellowship in the Ethics of Clinical Artificial Intelligence at SickKids, at the end of the decade, further enhanced the Department’s ability to address the ethical challenges associated with AI. McCradden quickly established herself as a leading voice in AI ethics globally and put SickKids on the map as a leader in AI Ethics. However, the unprecedented speed with which AI has progressed, along with fever pitch excitement about its potential, has led to competitive pressures that strain hard won ethical commitments to responsible development and implementation of new technologies.

The role of the Clinical Bioethics Associate

Until 2010, roles within the Bioethics Department included only bioethicists, administrative staff³⁰, and students/trainees. In contrast with other regions, such as the US, Canadian bioethicists are generally not physicians but hold graduate degrees from academic backgrounds like philosophy, theology, health sciences, social work or law, and have completed a clinical fellowship in bioethics. In the early 2010s, however, the Department formally incorporated a new role, that of the Clinical Bioethics Associate (CBA) — a clinician who has completed a graduate degree in bioethics and is on a career path that formally or informally includes protected non-clinical time to engage in bioethics teaching, policy development and scholarship. This role provides bioethicists with clinical partners that broaden disciplinary expertise brought to Department deliberations, reach, and embeddedness across the organization. Development of the role also gives a formal anchor to clinicians interested in having bioethics as their academic and research foci. The Department adopted a “hub and spoke” model consisting of three primary bioethicists (the hubs) and seven CBAs (spokes) supported by a Bioethics Advisory Committee³¹. The CBAs bring clinical specialty and bioethics expertise to the Department and a bioethics lens to their clinical, educational, policy, and scholarly engagement across the organization. The CBAs during this period included Mary Campbell (cardiac critical care

²⁹ These bioethicists include: Abbyann Lynch (philosophy), Mona Sidarous (Law), Francoise Baylis, (Philosophy and Health Policy), Christine Harrison (Philosophy), Mary Rowell (Religion), Randi Zlotnik Shaul (Law and Bioethics), Rebecca Greenberg (Nursing and Bioethics), James Anderson (Health Policy and Philosophy), Melissa McCradden (Neuroscience and Bioethics), Maram Hassanein (Pharmacy and Bioethics), and Andrew McFayden (Novel Therapeutics and Bioethics).

³⁰ A sample of administrative professionals who have worked with the Department of Bioethics include: Micheline Cox, Desta Ramlackhansingh, Parvizi Manji, Saima Navsariwala, Kathy Prokop, Gurleen Kaur, Samantha Singh, Hanifah Ahmad, and Han Banh.

³¹ The Department established a bioethics advisory committee in 2017 made up of approximately 20 staff from across the hospital and co-chaired by the Director of the Bioethics Department, first with Peter Cox and then with Kevin Weingarten. The committee meets quarterly, providing input on pressing ethical issues facing the hospital that could especially benefit from the range of contextual and disciplinary lenses brought by this diverse membership.

nurse), Lauren Chad (geneticist), Jonathan Hellmann (retired neonatologist and the inaugural Clinical Bioethics Associate), Andrew Helmers (critical care intensivist), Roxanne Kirsch (cardiac critical care intensivist), Sarah Lord (palliative care and complex care physician), Kevin Weingarten (palliative care physician and oncologist). In 2023, the model was described by Roxanne Kirsch and SickKids bioethics colleagues in the *Journal of Pediatric Ethics* (94).

Quality improvement and models of care

In recent years, bioethicists and Clinical Bioethics Associates have become members of an increasing number of committees and team discussions, providing opportunities to engage with ethical issues before they warrant a full consultation. Recognizing these contextual features of bioethics consultation data at SickKids provides a window into the local experience as well as context for emerging metrics of the field. With the move to the most recent version of the hospital's electronic medical record (EMR), and the fact that bioethics consult notes are part of the EMR, metrics going forward should be more accessible. In 2025 the Department introduced a new tracking system previously developed and in place at another Toronto academic health sciences centre. The hope is this may allow for useful comparison of metrics over time and benchmarking with other paediatric centres in the future.

Discourse on the legal and ethical issues raised by care-models, such as family-centred care, child-centred care, and the model adopted at SickKids, child and family centered care (95), were at the heart of many bioethics consultations, and subsequently became an important area of research and consideration within the Department. Inquiry and research in this area led to Zlotnik Shaul's 2014 edited volume, *Paediatric Patient and Family-Centered Care: Ethical and Legal Issues* (96). The book featured 18 chapters by 31 authors from across Canada and varied healthcare specialties exploring the ethical and legal synergies and tensions these models can create in a range of different contexts³². Shortly after, in 2018 Greenberg, with colleagues Aviva M. Goldberg and David Rodriguez-Arias, edited and published *Ethical Issues in Pediatric Organ Transplantation* (97). The book was the first in a Canadian context to specifically address ethical issues in paediatric organ transplantation. Both books were very well received by Canadian and international colleagues in paediatric healthcare and bioethics.

Addressing the SickKids 'truths' of truth and reconciliation

During this period, a significant commitment of the Department involved considering institutional involvement in harms propagated against Indigenous peoples in Canada, as a first step towards reconciliation. This is an important term that entered the public consciousness of Canadians, following the 2007 Indian Residential Schools Settlement Agreement which mandated the establishment of the Truth and Reconciliation Commission³³. One such harm distinctly tied to SickKids was its participation in nutritional experiments performed on Indigenous children in Canada at six residential schools between 1942 and 1952 (99). The Department of Indian Affairs Canada performed the experiments under the direction of two physicians, Percy Moore and Frederick Tisdall, the former a famed nutritionist and one of three paediatricians at SickKids who developed Pablum infant cereal in the 1930s (100). The impact of these experiments was documented by Canadian historian Ian Mosby (101) who found that Indigenous children participating in the study, without the informed consent of the children or their guardians, were denied adequate nutritional, medical, and dental care, leading to death and severe physical and mental trauma (101). SickKids acknowledged their involvement in a public apology issued in 2018:

The Truth and Reconciliation Commission of Canada states that without truth, justice is not served, healing cannot happen, and there can be no genuine reconciliation between Indigenous and non-Indigenous peoples. It is with this belief in mind that SickKids wishes to acknowledge harmful aspects of the hospital's history with Indigenous peoples as a first step on the path of reconciliation. Between 1942 and 1952*, on behalf of the Department of Indian Affairs of Canada, SickKids physician Dr. Frederick Tisdall led nutritional experiments on malnourished populations in Indigenous communities and residential schools. During these experiments essential vitamins were withheld from children who needed them and regular physical examinations may have been confusing, painful, and potentially traumatic. The experiments were conducted without children or their parents' consent, and by modern standards of medical research ethics would not have been approved. Findings of the studies did little to alleviate the underlying causes of malnutrition for Indigenous children, and for most, the health risks experienced over the course of the studies outweighed any benefits received. As an organization, SickKids bears responsibility for having allowed this unethical research to occur (102).

The apology also acknowledged the 2015 closure of its Motherisk Drug Testing Lab after it was determined the lab's testing procedures, used by the Ontario child protection system, did not meet appropriate standards for forensic use. A report on the harmful effects of the reliance on hair testing in child protection court cases ordered by the Attorney General of Ontario found drug testing had been disproportionately imposed on Indigenous families in the provincial child protection system and in legal

³² Featured topics in the book include child consent to research, resource allocation, cultural and religious conflict, decision-making in the Neonatal Intensive Care Unit, and partnerships when treating adolescent anorexia.

³³ The Commission gathered testimony from over 7,000 survivors of the Residential School System and published its entire six volume final report and calls to action in 2015. The National Centre for Truth and Reconciliation at the University of Manitoba maintains the public national record of their work (98).

proceedings (103). The apology echoes sentiments expressed by Indigenous children's rights activists, like Cindy Blackstock³⁴, who have expressed that, to serve the interests of Indigenous children, we need to challenge the myths we tell ourselves to justify past actions we deem abhorrent. By recognizing contemporary injustices against Indigenous peoples as deliberate choices and patterns, we have the power to disrupt and transform behaviours and relationships (105). Other healthcare institutions across Canada are also being called on to examine how they can reconcile their past relations with Indigenous children with their current efforts to build reciprocal relationships grounded in honesty about anti-Indigenous racism, and respect for Indigenous community-based knowledge and experiences (106,107). Today, the Bioethics Department continues to explore what the spirit of truth and reconciliation looks like, and what it calls us to do in our creation of practices, policies, and relationships. The Department has had membership on the hospital's Indigenous Health Council, engaged in external training, and collaborates by integrating Indigenous knowledge into offerings such as Bioethics Grand Rounds Book Reviews, Bioethics Year-In-Review, Bioethics Week, and Departmental activities in consultation, policy development, graduate student support, research and scholarship.

Medical assistance in dying

Another notable legal development in the 2010s was Canada's legalization of Medical Assistance in Dying (MAID), in 2016, following the SCC Carter decision (108). MAID legislation opened discussion to a myriad of ethical concerns. In 2016, the Canadian Council of Academies was tasked by the federal government with examining three categories left outstanding by the legislation. These included the use of advanced directives, requests wherein the sole underlying illness is a mental disorder, and the question of eligibility of mature minors. The Council selected experts from across Canada, including Zlotnik Shaul, to serve on the Expert Panel Working Group for MAID for Mature Minors. The group released their report on the mature minor question in 2018, "The State of Knowledge on Medical Assistance in Dying for Mature Minors" (109). In 2019, PhD candidate Carey De Michelis along with Adam Rapoport (Medical Director of Patient Advanced Care Team-PACT) and Zlotnik Shaul — as co-leads of the SickKids MAID Policy Development Working Group for legally eligible 18-year-olds — published a paper on the emerging legal and ethical landscape of MAID for eligible 18-year-olds receiving care in a paediatric hospital (110). Public discourse about MAID raised questions and concerns about the morality and capacity of a legally qualifying 18-year-old to access MAID. Discussions about whether an adolescent should be considered capable of making decisions linked to their death were not new questions for bioethicists at SickKids. Decades earlier in 1992, Lynch hosted two "Everyday Ethics" sessions on the topic (111,112). Canada continues to discuss the ethics of mature minors becoming eligible to access MAID at some point in the future. In 2023, Zlotnik Shaul was invited back to parliament to present on ethical issues associated with MAID for mature minors, as an expert witness on behalf of SickKids to the Senate's Special Joint Committee on MAID (113).

The responsible integration of artificial intelligence

During her postdoctoral fellowship at SickKids on the ethics of clinical artificial intelligence³⁵, McCradden and Anderson led the development of a research ethics-based pipeline for the responsible integration of clinical AI (114,115). McCradden was subsequently hired as a bioethicist with the Department in 2019, adding AI ethics expertise to the bioethics team at a critical time. SickKids centred precision child health, a mission which involves leveraging machine learning and big data to individualize diagnosis and treatment, as a cornerstone of their 2020-2025 Strategic Plan (116). In 2022, McCradden was appointed as the Director of Artificial Intelligence in Medicine at SickKids. Ethical dimensions of this work included public and patient/family perspectives on AI and the aforementioned work on clinical integration of AI in healthcare, among several others³⁶. Collaborations with international colleagues produced guidelines for clinical trial protocols for interventions involving AI (138) and reporting guidelines for early-stage clinical evaluation of decision support systems driven by AI (139). In 2024, McCradden took on the role of Research Fellow in AI Ethics at the Australian Institute for Machine Learning and AI Director at Australia's Women's and Children's Health Network, while retaining a research appointment at SickKids. In 2024, Anderson's responsibilities expanded to include Ethics Lead for Artificial Intelligence at SickKids, a leadership role in AI ethics consultation (clinical, organizational, research), AI ethics education, and the development of ethically informed frameworks, platforms and tools to facilitate the implementation of AI into clinical care. This journey reflects an institutional appetite for embracing AI to improve care and how the Bioethics Department acknowledged the importance of embedding ethics into this process by co-creating this fellowship and later committing to making ethics central to the development of AI at the hospital. This is another example of collaboration with other departments, and the desire to integrate ethics within all areas of the hospital.

One of the considerations within the bioethics team rests in the reflection around technological solutionism and the moral mandate of bioethicists to provide impartial, neutral ethical analysis in a situation where the institution has committed itself to a particular technology. With AI embedded in the 2025 SickKids Strategic Directions, the pressure to ensure it delivers value

³⁴ Cindy Blackstock, a member of the Gitksan First Nation, is an Indigenous children's rights activist and Executive Director of First Nations Child & Family Caring Society of Canada, Associate Professor & Director of FNCARES (First Nations Children's Action Research and Education Service) at the University of Alberta and Professor in McGill's School of Social Work. Blackstock has collaborated with other Indigenous leaders to assist the United Nations Committee on the Rights of the Child in the development and adoption of a General Comment on the Rights of Indigenous children (104).

³⁵ To address contemporary issues and advancements, in 2018, SickKids partnered with Vector Institute for Artificial Intelligence, a Toronto based independent, not-for-profit organization affiliated with the University of Toronto to create a first-of-its-kind fellowship opportunity, a Postdoctoral Fellowship in the Ethics of Clinical Artificial Intelligence. The inaugural AI ethics fellow, Melissa McCradden joined The Department as a bioethicist in 2019.

³⁶ Other areas of research in the Department include informed consent by paediatric patients to the collection and analysis of data (117), reporting of "ethics methods" in clinical research (118,119), the ethics of whole genome sequencing in paediatrics (120-123), the ethical translation of novel therapeutics (124-126), algorithmic bias/equity-promoting solutions for point-of-care decision-making using AI (127,129), the explainability of AI algorithms (127), evidence for the promise of AI in psychiatry (129), the value of standards for health datasets in AI-based applications (130), and further nuances on the ethics of AI application in paediatric healthcare settings (114,115,131-137).

almost inevitably leans on not just bioethicists but all SickKids staff. Against this backdrop, bioethicists must navigate the competing tensions between delivering on the institution's strategic vision while holding the line of the profession in providing impartial ethical analysis.

The COVID-19 pandemic

On March 11, 2020, the World Health Organization (WHO) declared the COVID-19 outbreak a pandemic³⁷, urging countries to activate and scale up their emergency response mechanisms and prepare their healthcare systems (140). Circumstances created by the pandemic exacerbated existing ethical tensions in the Canadian healthcare system producing an environment which challenged the ethical judgment of providers, patients, and families. The ways in which the pandemic uniquely affected the paediatric population and their families prompted the Bioethics Department's involvement with related internal and external dialogue, policy, advocacy and scholarship. Examples include: the development of pandemic family presence policies, vaccine mandate policies, education, and strategies to navigate vaccine hesitancy (142), approaches to navigate moral distress among providers, the accommodation of adult patients in a temporary adult ICU, and consultation support on duty to care and resource allocation concerns in the paediatric surgery backlog (143,145). On a provincial advocacy level, Zlotnik Shaul was appointed to the Ontario Covid-19 Bioethics Table to bring the lens of paediatric ethics to support decision-making for the province on key pandemic related policies and recommendations affecting children and their families³⁸.

Precision child health, and expanding engagement in health equity & artificial intelligence

Precision Child Health (PCH) became a SickKids priority. It seeks to integrate patient and family data seamlessly into a responsive learning health system, advancing our capacity to deliver individualized care. This integration aims to enhance diagnostic speed, therapeutic precision, and predictive insight, ultimately refining how we meet each patient's specific needs. PCH leadership recognized that the ethical dimensions of this approach to care must be considered as the infrastructure and governance are being created. To that end, positions such as Ethics Research Analyst and Ethics Lead for PCH were established.

Alanna Goldstein was hired in 2022 as the Ethics Research Analyst. With expertise in health education and media literacy, Alanna works in partnership with the bioethics team to understand the ethical, legal, and equity issues that affect the SickKids' patient, family, and staff communities, and to ensure these issues are considered and addressed in the development and implementation of PCH initiatives. In 2024, the Department made significant additions to the team. Maram Hassanein joined as a bioethicist, bringing expertise and engagement at the intersection of healthcare ethics and religion, health equity, end-of-life care, pharmaceutical ethics (148), and global ethics. An Ethics Lead in PCH role was created and filled by Andrew McFadyen who brings expertise grounded in parental and advocacy experience with patients, families, governments, industry, hospitals and researchers along with bioethics training and international engagement to broadening access to novel therapeutics and PCH. In the short time since his arrival, McFadyen (working closely with Anderson, Pat Furlong, and PhD candidate Lucie Perillat) developed and published a model for the development, administration, and evaluation of individualized therapies (149). Each of these roles reflect recognition of, and the organization's investment in, specialized attention to some of the most ethically complex issues in paediatric bioethics.

CONCLUSION — LOOKING TO THE FUTURE

The process of researching and writing this manuscript enhanced our understanding of the contexts that have shaped paediatric bioethics within and beyond SickKids. As we delved into discussing the perceived ethics scandals in SickKids' history, we often paused to consider whose interests were prioritized and what this focus revealed about societal and institutional inequities. In recounting the work of the Department — be it in consultation, research, education, policy development, or training the next generation of bioethicists, clinicians, researchers, health lawyers and academics — we gained a deeper appreciation of the values prioritized by the Department and the institution more broadly. We recognized that the pervasive collaborative spirit across all members of the Department has consistently facilitated and enhanced bioethics work. Members appear to have always freely shared with one another insights from their own disciplinary training with respect and humility, raising the quality of Departmental output. The evolution of the Department's work engaged with societal and legal shifts regarding child rights.

Institutional memories and culture are often passed down from person to person, as was the case in the Department. Recognizing the importance of documenting the journey of the Department, we embarked on this project not only for our own learning but for future bioethicists, the SickKids community, and for potential scholars to have access to a window into the development of bioethics at SickKids. As the field of bioethics continues to move towards a form of professionalization, appreciating dimensions of its development becomes crucial for contributing to future trajectories. This project illustrates the significance of recording both achievements and challenges within bioethics; our hope is that other bioethics programs will be inspired to document and disseminate their own unique experiences. The examination and preservation of institutional culture, memories, policies, and practices can contribute to informing an intentional and mindful progression of the discipline.

³⁷ In July of 2020, a special task force led by the Chief Science Advisor of Canada released their report on the science concerning children as vectors for the spread of COVID-19 (141).

³⁸ The Bioethics Table produced briefs on consent for the vaccination of youth aged 12-17 (145), the ethics of paid sick leave during the pandemic (146), and priority setting for personal protective equipment, among others (147).

While lessons we have learned (and are still learning) through this unique inquiry will continue to crystalize, at this time we recognize that hospital-based bioethics is not a solitary activity. The impact or quality of the engagement is dependent upon the unique qualities of the bioethics team members, their relationships with patients, families, colleagues and trainees, the support of institutional leadership, the political climate and opportunities within and outside the institution, and the evolving culture of the organization. At a time when burnout of those working in healthcare is at an all-time high, we have come to better appreciate the significance of collegiality, trust and support between members of a bioethics team. Like with any healthcare team, SickKids bioethics team members have, over the course of their careers, experienced personal health issues, family challenges, the loss of loved ones, and a range of intersectional vulnerabilities. The collaborative team dynamic and nurtured relationships allowed members to work in their roles, supported by professionalism and compassion, while facing their personal circumstances.

As we envision the future, we anticipate learnings from this rich chronology being solidified through ethics work in AI, Precision Child Health, best interests of the child in the context of population diversity, leadership ethics, clinician and family wellbeing and more. The future of the Department is bolstered by the contributions of numerous staff and trainees both within and outside the Department. Service, collaboration, leadership, and adaptability have characterized the Department's history thus far and all indications point to it being the *modus operandi* of chapters to come.

No written chronology of a bioethics department can be fully comprehensive. There are significant conversations, "ah-ha" moments and even unspoken experiences of bearing witness that are too nuanced to fully capture or document. Yet these experiences strengthen the thread that links each generation of a bioethics service to the next. While the work of a bioethics department contributing to the multiple facets of complex health care organizations can be intellectually challenging, emotionally heartbreaking, and at times very stressful, the experience of working in community at the intersection of such profound human experiences is nothing short of a privilege. The gratitude that comes from looking back at the opportunity to work with others who responsibly carry the weight of such space with care, makes both the work, the looking back and the looking forward worthwhile.

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Conflicts d'intérêts

Aucun à déclarer

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Conflicts of Interest

None to declare

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APPENDIX 1

Last Name, First Name	Credentials	Role Linked to Bioethics Dep at SickKids
Anderson, James	MHA, MA, PhD, Philosophy	Bioethicist, Ethics Lead for AI
Barker, Geoff	MB, BS a	Chair Ethics Committee
Baylis, Françoise	CM, ONS, FRSC, FISC	Bioethicist
Campbell, Mary	RN, BScN, MHSc, cardiac critical care nurse	Clinical Bioethics Associate
Chad, Lauren	MDCM, MHSc, FCCMG, FRCP (C), geneticist	Clinical Bioethics Associate
Charland, Louis	PhD	Bioethicist
Cox, Peter	MBChB, DCH, FFARCS (UK), FRCP(C)	Inaugural co-chair Bioethics Advisory Committee
De Michelis, Carey	MA, PhD	PhD(c), research coordinator
Goldbloom, Alan	BSc, MD Associate Pediatrician in Chief, Exec VP & Chief Operating Officer	Executive lead for Bioethics Department
Goldstein, Alanna	MA, PhD	Ethics Research Analyst, Precision Child Health
Greenberg, Rebecca	RN, PhD, Bioethics	Bioethicist, Researcher
Harrison, Christine	PhD, Philosophy/Bioethics	Bioethicist, Director
Hassanein, Maram	RPh, MA, MSc, Bioethics, BPharm	Bioethicist
Hellmann, Jonathan	MBBCH, FCP(SA), MHSc Neonatologist	Clinical Bioethics Associate
Helmets, Andrew	MDCS, MHSc., FRCP (C) paediatrics intensivist	Clinical Bioethics Associate
Huang, Lennox	CMO, VP, Educ, Med & Academic Affairs	Executive lead for Bioethics Department
Huble, Pam	MSc, BScN, VP Interprofessional Practice, Learning Institute	Executive lead for Bioethics Department
Keatings, Margaret	RN, MHSc, Chief of Nursing & Interprofessional Practice	Executive lead for Bioethics Department
Kirsch, Roxanne	MD, MBE, FRCP (C), FAAP cardiac intensivist	Clinical Bioethics Associate
Kunicki, Louis	RN	Researcher
Laxer, Ronald	MDCM, FRCPC Physician, VP Medical and Academic Affairs	Executive lead for Bioethics Department
Lord, Sarah	MD, FRCP (C), MHSc PACT, (palliative care), Complex Care	Clinical Bioethics Associate
Lynch, Abbyann	CM, OOnt, LMS, PhD, LLD (Hon.), DSL. (Hon.)	Bioethicist, Inaugural Director
McCadden, Melissa	PhD Neuroscience, MHSc Bioethics	Bioethicist, Director AIM
McFadyen, Andrew	BA, BEd, MHSc, Bioethics, HEC-C	Ethics Lead for Precision Child Health, Bioethicist
Perillat, Lucie	HBSc, PhD(c)	Trainee
Rapoport, Adam	MD, FRCPC, MHSc Bioethics, PACT	policy development co-lead - MAID
Ritchie, Zoe	MA, PhD	Trainee, research coordinator
Rowell, Mary	RN, MA nursing ed, MA ethics and law, cardiac critical care nurse	Bioethicist
Sidarous, Mona	LLB, LLM	Bioethicist
Turner, Lucie	MBBS, MHSc, MA (cantab)	Bioethics Fellow — Paediatric Eating Disorders Ethics
Weingarten, Kevin	MD, FRCP (C), MHSc PACT	Clinical Bioethics Associate, co-chair BAC
Williams, Allison	PhD	Bioethicist
Zlotnik Shaul, Randi	JD, LLM, PhD (health law, bioethics)	Bioethicist, Researcher, Director, co-chair BAC

APPENDIX 2

