For the purpose of discussion only

Office of Child and Family Service Advocacy

Consent and Confidentiality in Health Services: Respecting the Child's Right to be Heard

November 2003

“We should have a say because it’s about us. It’s our life.”
(Youth in Care, 2003)

Amanda Hotrum, Principal Researcher
Jill Magazine, Advocacy Officer
Hari Viswanathan, Advocacy Officer
Judy Finlay, Chief Advocate
“It is important for us to have a say because some kids in care don’t have a family. We’re the only one to have a say.”

“It’s our bodies.”

“We should be informed about what is happening to us.”

“Not everybody should know what’s going on with your body.”

“I needed someone to advocate for me because I couldn’t always advocate for myself.”

“When you go into care, they assume you did something wrong and label you.”

“They think every kid in care is crazy.”

“If you have a kid in care, care for the kid. They are not insane.”

“Staff make minor mistakes but when you are dealing with kids, it’s big pressure time. They are huge.”

Youth in Care, 2003
# Table of Contents

I. Executive Summary

II. Introduction 1

III. Methodology 1

IV. A Review of the Literature
   1. Conceptualising consent 3
   2. The ability of children and adolescents to consent 4
   3. The benefits and risks of autonomous decision-making and confidential services 6

V. The Law, Legal Remedies and Lived Reality: Key Discrepancies 8
   1. Consent and privacy law in Canada and Ontario 8
   2. Legal remedies for children 11
   3. The experiences and concerns of children in care 12

VI. Moving Towards Critical and Ethical Understandings of Consent: Some Essential Principles 14
   1. Presumption of capacity 14
   2. Autonomous decision-making 15
   3. Assessing capacity 15
   4. Developing capacity 15
   5. Consent as a process 16
   6. Valid consent 16
   7. Confidential health services 17

References 20
Executive Summary

Consent and Confidentiality in Health Services: Respecting the Right to be Heard, seeks to examine the key issues regarding consent and confidentiality for children and adolescents in care and to provide the Office of Child and Family Service Advocacy (OCFSA) with the knowledge and tools to advocate for adolescents and children on these issues. The body of the paper is divided into three sections:

The first section is comprised of a review of the literature on consent and confidentiality in the delivery of health services to children. The two dominant perspectives in this area, the Welfare Approach and the Individual Autonomy Approach are discussed. Reconciling these two approaches in a way that respects children's rights, while ensuring that children do not become isolated from their families or communities, is identified as being the primary challenge for the children's service sector.

There is overwhelming evidence to suggest that even young children have the capacity to consent to health-related services provided the nature and quantity of information presented and the form and source of the presentation are appropriate. The literature has outlined a number of benefits associated with treating competent children as autonomous decision makers who have the cognitive capacity to adequately understand and deal with serious and confidential health information. These benefits include the reduction of anxiety, improved family functioning, increased intimacy, long-term gains in psychosocial adjustment, and increased access to health services for children, particularly sexual health services.

The second section examines the state of consent and privacy law in Ontario and Canada and the experiences and concerns of youth in care. While there have only been a few reported court decisions in Canada dealing with issues of consent to treatment for children, these cases have clearly stated that there is no age below which children cannot authorize their own care. Children should be presumed capable to do so unless there are reasonable grounds to believe otherwise.

Several sections of Ontario's Child and Family Services Act which have not kept pace with the changes in consent law are discussed. These sections continue to mislead those in the children's service sector who may not be trained in the law of consent. The paper uncovers that the Consent and Capacity Board (CCB), the main avenue available in Ontario for children to address findings of incapacity made by health care practitioners, rarely receives requests for hearings from children. Furthermore, legal practitioners agree that children are seldom advised of their right to appeal.

In the absence of legislative certainty about the disclosure of health information, Children's Aid Societies and children's residential facilities have developed inconsistent and variable policies and procedures across the province. Moreover, the authors raise a point of concern over the few formal avenues that exist for children who feel that their health information has been disclosed inappropriately.
In consulting with youth in care, the authors found that the overwhelming majority of youth interviewed felt that while in care they had little control over their health, were denied crucial information about their health status, had little privacy when it came to health information, and had difficulty advocating for themselves in health-related matters.

In the final section, a set of essential principles to guide the work of the OCFSA as it advocates for children in the care system around issues of consent and confidentiality are listed. These principles are as follows:

1. Presume that children are capable of consenting, (unless there are reasonable grounds to believe otherwise), regardless of age, disability, or the administration of psychotropic drugs, although such factors may be relevant in the assessment of capacity.

2. Ensure that children's rights to make their own health decisions are respected and that children are advised of their right to have findings of incapacity reviewed by the CCB.

3. Ensure that determinations of capacity are based on the ability of the person to understand the information that is relevant to the treatment decision and appreciate the reasonable foreseeable consequences of the decision or lack thereof.

4. Ensure that children are given the opportunities and assistance they need to develop their competence to make health decisions.

5. Ensure that the consent process involves an ongoing and active dialogue between the child, medical practitioner and, in some cases, the guardian or another adult.

6. Ensure that consent is informed, related to the treatment, voluntary and free from misrepresentation or fraud.

7. Ensure that children's service agencies and providers develop uniform privacy and access to information policies based upon the ten principles of the Canadian Standards Association's Model Code for the Protection of Personal Information.
I. Introduction

There is growing consensus within the medical, legal and social welfare sectors that children should have decision-making powers over their own health and access to confidential health services. Canadian law has also shifted in this direction: viewing children as autonomous beings and acknowledging the decision-making capacity of those considered 'mature minors'. However, many service providers and guardians continue to doubt the capacity of children to make key decisions regarding their health and are concerned about the delivery of confidential health services to minors.

The ability to give consent continues to be tied to arbitrary and inconsistent age indicators. The lack of clarity regarding issues of consent and confidentiality is compounded for children in care\(^1\) who tend to have a number of care-givers, may experience multiple placements, and may reside in residential care or custody facilities. Children and adolescents in care also face unique challenges regarding consent and confidentiality since they may be more vulnerable to coercion and may have difficulty asserting their rights and being heard.

Despite calls to establish clearer guidelines on the issues of consent and confidentiality for children and adolescents, this change has not come to bear. As a result, there is great variability in the knowledge and understanding of these issues in the children's services sector. As long as basic standards regarding consent and capacity for children and adolescents remain unwritten matters of judgement, they will fluctuate with changing resources, priorities and personnel. As such, the protection of children's rights regarding consent and confidentiality will remain inadequate.

This paper seeks to examine the key issues regarding consent and confidentiality for children and adolescents in care and to provide the Office of the Child and Family Services Advocacy (OCFSA) with the knowledge and tools to advocate for children and adolescents on these issues. Part one of the paper includes a literature review of the key issues around consent and confidentiality in health care for children, with a particular emphasis on issues of relevance for children in the care system. Part two of the paper examines Canadian and Ontario law on consent and confidentiality for children, considers the remedies available to children for addressing issues of consent and confidentiality and discusses the discrepancies between the law and the lived reality of children in the care system. Part three of the paper outlines some essential principles for advocating for children in care.

II. Methodology

This paper was developed in consultation with the OCFSA, legal practitioners in the areas of child welfare and mental health law, and youth in the care system. Primary and secondary data collection methods were used. Primary data collection included an examination of provincial statutes and non-governmental policies dealing with issues of consent and confidentiality for children. Primary data was also collected by conducting

\(^1\) ‘Children in care’ refers to children in the child welfare, children’s mental health or youth criminal justice systems.
one focus group with five OCFSA Advocacy Officers and interviewing the following key informants:

- Cheryl Milne Barrister and Solicitor, Justice for Children and Youth
- Bruce Rivers Executive Director, Metro Toronto Children’s Aid Society
- Kristina Reitmeier Director of Legal Services, Metro Toronto Children’s Aid Society
- Marvin Bernstein Barrister and Solicitor
  Ontario Association for Children’s Aid Societies
- Suzan Fraser Barrister and Solicitor
- D’Arcy Hiltz Barrister and Solicitor
- Kaca Henley Independent Child Advocate

Data collection also came through direct feedback from youth regarding their experiences with consent and confidentiality issues. Two focus groups were conducted with a total of eighteen youth that are currently, or have been, in the child welfare, youth criminal justice and/or children’s mental health systems. The youth were recruited from the Greater Toronto Area. They ranged in age from 16 to 26 and were a mixed group in terms of gender, ethnicity and ability.

The secondary data collection included a review of the medical, legal and social welfare literature on consent and confidentiality from 1980 to present.

Finally, written feedback on a draft version of the paper was requested and received from the following persons:

- Kaca Henley Independent Child Advocate
- Dick Meen Clinical Director, Kinark Child and Family Services
- Bruce Rivers Executive Director, Metro Toronto Children’s Aid Society
- Marvin Bernstein Barrister and Solicitor
  Ontario Association for Children’s Aid Societies
- Carol Appathurai Manager, Health Information Privacy Unit
  Ministry of Health and Long-Term Care

III. A Review of the Literature

In the last twenty years, there has been extensive debate within the legal, medical and social welfare literature around the issues of consent to treatment and confidential health services for children. However, the literature has failed to consider the unique challenges that children in the child welfare, youth criminal justice or children's mental health systems face. This section outlines the key themes found in the literature on consent and confidentiality in health services for children, with a particular emphasis on the themes that are relevant for children in care. The themes that are discussed include: ways of conceptualising consent, the ability of children to consent, and the
benefits and risks associated with autonomous decision-making and confidential health services for children.

1. Conceptualising consent

Two dominant perspectives generally inform the literature on consent and confidentiality in health services for children. The Welfare Approach takes the position that power can be exerted over children by adults as long as it is exercised in a manner that is consistent with the child's welfare or best interests. This approach is largely paternalistic as it recognises the obligation to consult with children but does not give the child the right to autonomous decision-making (Handford, 1988). This perspective depends heavily on the perception of what is good for children, a notion that is socially defined and continually changing over time and space.

The major critique of this perspective is that it provides adults with a great deal of power over children and permits the invalidation of children's decisions on discretionary and subjective grounds (Handford, 1988). This is particularly problematic given that caregivers may have difficulty distinguishing their own personal or professional aims from the best interests of a child, a dilemma that is only intensified by the fiscal constraints of the contemporary children’s services sector. In a Canadian context, the Welfare Approach has also been critiqued for abrogating common law, the Charter of Rights and Freedoms and the U.N. Convention on the Rights of the Child with respect to the rights of children.

The second dominant approach, the Individual Autonomy Approach, is informed by the human rights perspective that all individuals have a basic legal and moral right, irrespective of age, to be free from bodily harm and interference. As such, this perspective advocates for the rights of children to have decision-making power over their own health and to have their privacy protected. Rather than focusing on best interests, this perspective argues that issues of consent and confidentiality should be approached from the premise that children have a right to self-determination, personal dignity and integrity of the self.

Critics of the Individual Autonomy perspective argue that children lack the identity development and developmental capacity to make autonomous decisions (Foreman, 1999; Dickenson and Jones, 1995). However, resistance to viewing children as autonomous beings is also informed by the social construction of childhood as a period of relative innocence and vulnerability that requires a protective umbrella of adult control and intervention. This construction idealises the family as a safe haven and protective force for children. Lingering notions of children as property and the reluctance to intrude on parental interests and desires, particularly where they contribute to social order and nation-building, also contribute to resistance to the Individual Autonomy perspective.

While critiques of the Individual Autonomy approach generally stem from the political Right, critical theorists on the Left have also raised some important challenges to frameworks that emphasise individual autonomy. Specifically, theorists point to the
failure of individual autonomy approaches to account for the complex relationships between families, communities and systems of domination. Families have been, and continue to be, a key site in which racism, sexism, homophobia, ableism and classism have been enacted on marginalized peoples. Given this reality, for some communities maintaining families has become an act of resistance. Ng (1993) reminds us that family and kinship, perceived or real, are means people deploy to exert their domination but also to overcome their subordination. This critical perspective requires that we begin to conceptualise families as both sites of violence towards children and as important sites of resistance to oppression.

The challenge for the children’s services sector is to reconcile these two approaches in a way that respects children's rights to be heard and to be treated as competent subjects while ensuring that children do not become isolated from their families and communities. Smith (1997) argues that the best way to reconcile the issue of rights versus interests is to understand that children are the most accurate arbiters of their own best interests. If we accept that children know something about what is required to enhance their own well-being, then it is imperative that we enable them to express their views and give them appropriate rights in decision-making. Mahawald (2000) also provides an excellent response to the challenge of reconciling rights-based ethics and relational-care ethics. He argues that these two perspectives are not mutually exclusive if we conceptualise an ethic of care as being committed to maintaining relationships, while an ethic of justice to ensuring that the relationships are not exploitative.

Within the consent literature, there has also been a move to conceptualise consent as something that is developed rather than discovered (Mill, 2002; Smith 1997; Weir & Peters, 1997; Group for the Advancement of Psychiatry (GAP), 1989). The literature argues that competence can be developed by providing children with progressively more responsibility for their lives, ultimately culminating in their competence at self-governance (Mill, 2002; Schultz, 1993). This could include the gradual and appropriate escalation of involvement in treatment decisions, offering increasing responsibility for treatment compliance, and providing opportunities to ask and answer questions during health appointments (Weir & Peters, 1997). Smith (1997) reminds us that children will not accumulate knowledge and experience unless permitted the freedom to make and learn from mistakes. Thus, competence depends, to some extent, on whether children have actually been given real choice and permitted to exercise it.

In addition to viewing consent as something that can be developed, the consent literature has also begun to conceptualise consent as an ongoing process rather than an isolated event. Schultz (1993) argues that when considering consent we must think less in terms of receiving informed consent at a particular moment and more about encouraging dialogue between children, health care professionals, and caregivers. This perspective requires that we view consent forms, not as the sum total of the consent process, but merely as evidence that the process has been engaged. Weir and Peter (1997) point out that strong, trusting, respectful relationships between physicians, children and guardians are crucial to engaging in consent as a process.
2. The ability of children and adolescents to consent
There is overwhelming evidence to suggest that many children have the developmental capacity to consent to health-related services (Smith, 1997; Schultz, 1993; Franklin, 1995; Lyon, 1993; Alderson 1994; Alderson and Montgomery, 1996; Dickenson and Jones, 1995; Weithorn & Campbell, 1982). Traditional cognitive theories argue that decision-making with respect to medical treatment requires the kind of abstract thinking that is characteristic of the concrete and formal operations stages (Piaget, 1968; Inhelder & Piaget, 1958). While Piaget originally posited that these stages are reached between seven and twelve years of age, scrutiny of Piaget's metapsychology over the last thirty years has indicated that children may have the ability to consent much earlier (GAP, 1989).

In their landmark study, Weithorn and Campbell (1982) tested developmental differences in competency to make health decisions. They found that there was no difference between fourteen-year-olds and adults in their level of competency. They also found that although nine-year-olds did not fully consider as many critical elements as adults and were less competent on the ability to reason and understand treatment information, they identified the salient factors of the situations presented and expressed clear and sensible treatment preferences. Those critiquing the Weithorn and Campbell study have questioned their use of hypothetical scenarios in a laboratory. However, many health and legal practitioners who work with children agree that even young children often have the capacity to consent to their health care (GAP, 1989; Schultz, 1993; Dickenson, 1994; Melton, 1983; Franklin, 1995; Lyon, 1993; Mill, 2002; Weithorn and Campbell, 1982).

However, the ability to consent does not occur in a vacuum. Similar to adults, the capacity of children is influenced by a complex interplay of individual and social factors. For example, the nature and quantity of information presented, the form of the presentation, and the source of the information provided all impact children's ability to consent (Melton, 1983; Smith 1997; GAP, 1989). Thus, even children with the cognitive capacity to consent may not be able to engage in the consent process if it is conducted in an inaccessible way. Handford (1988) also argues that the social maturity of a child is a key factor in the ability to consent. Social maturity could be developed by living independently, handling one's basic needs, or seeking medical services independent of a guardian. Social maturity may be a crucial factor for determining the capacity of children who differ from their peer group in cognitive development but who have had extensive life experience.

The extent to which children have a secure identity, a characteristic that is generally not attributed to children, has also been cited as a key factor in the capacity to consent. However, Smith (1997) reminds us that identity formation is an ongoing process and argues that there is little reason to believe that this process is disrupted and replaced with a fully formed, fixed and stable identity simply because one has reached the age of adulthood. There are also differing interpretations in the literature on the impact of trauma on children's decision-making capacity. Smith (1997) argues that traumatic events may de-stabilise the emotional and cognitive world of a child, thereby inhibiting
their ability to exercise autonomous decision-making. However, Weir and Peters (1997) argue that years of physical and psychological trauma frequently leave children mature beyond their years. At the very least, trauma often creates multiple opportunities for children to think about what is important to them and to reflect on complex and often painful life situations.

3. The benefits and risks of autonomous decision-making and confidential health services

Within the literature there has been substantial discussion of the risks and benefits of providing competent children with decision-making autonomy and confidential health services. The discussion about the risks associated with treating children as autonomous subjects has largely revolved around concerns about causing children undue stress: including immediate physical trauma and prolonged anxiety, sadness and despair. However, this argument relies on the fallacious assumptions that children do not have the cognitive capacity to adequately understand health information and that it is protective to shield children from information regarding their situation. Lipson (1993) argues quite the opposite, stating that the disclosure of serious health information rarely results in a loss of will to live or a resulting depression that lowers the child’s immune response. In fact, he argues that the disclosure of serious health information can actually produce positive results such as the reduction of anxiety, improved family functioning, increased intimacy and long-term gains in psychosocial adjustment. Further, the discussion of health matters before the final stages of illness allows children to avoid a sudden, harsh, and lonely confrontation with their health status.

Lipson also states that medical practitioners frequently observe children who have been denied health information listening in on conversations, asking other patients about their conditions and slipping health-related questions into conversations in an effort to develop a better understanding of their bodies and lives. He also remind us that most school age children have the capacity to deny or avoid information that is harmful to them. Finally, Lipson argues that concerns about the inability of children to cope with serious health information frequently reflects the inability of adults to process this information.

The discussion regarding the risks of confidential health services for children has been centred on concerns that young people will be encouraged to engage in reckless health behavior and that parental support and guidance will be undermined. Not surprisingly, this discussion has largely revolved around sexual health services for young women and has included allegations that confidential services encourage young women to engage in sexual activity at an earlier age and more frequently. However, there is little empirical evidence to support this argument (Alan Guttmacher Institute (AGI), 1994). Rather, young people attending family planning clinics with special protocols for confidentiality have fewer problems with contraceptive use, have high contraceptive continuation rates and have low pregnancy rates (AGI, 1994).

Regarding the exclusion of parental input into the health decisions of minors, Albisa (1996) argues that the majority of young women making important sexual health
decisions voluntarily inform their guardians. Further, decisions to exclude guardians from the process often reflect concerns that disclosure would trigger physical violence and/or coercion regarding their decisions (Henshaw and Kost, 1992). Thus upon closer scrutiny, many of the alleged risks associated with treating competent children as autonomous decision-makers and providing them with confidential health services are more a reflection of the anxieties of adults than genuine risks posed to children.

The literature has outlined a number of benefits associated with treating competent children as autonomous decision-makers and providing confidential health services. These benefits include increased access to health services for children, particularly sexual health services. It has been well documented that children and adolescents may delay or forgo care, especially in the areas of sexual health, substance abuse, emotional problems and child maltreatment, if the consent or notification of a guardian is required (Albisa, 1996; Greydonus and Patel, 1991; Cook and Dickens, 2000; Cheng, Savageau, Sattler & DeWitt, 1993; Demetriou & Kaplan, 1989). Increasing access to health care for adolescents is a critical project given the extreme disadvantages adolescents face, compared to other age groups, in accessing these services (Garrison, 1989).

Increasing the decision-making autonomy of children may also greatly improve the treatment outcomes of health services for children. As children become active participants in the health services they receive, they are motivated to perform well, are more likely to follow through on treatment plans, and are less likely to prematurely terminate their treatment (Melton, 1989). Further, confidential health services facilitate the development of accurate diagnoses and appropriate treatments by enabling medical practitioners to gather more complete information (Sigman, Silber, English & Gans Epner, 1997).

Providing children with decision-making autonomy and confidential health services may also respond to the unique needs of children for validation, independence, and self-determination. While there has been limited research on the effects of self-determination on children, intuitively it could be argued that it increase children's self-esteem, enhances moral development, gives voice to children's values and ideas, and empowers children to gain control their own lives (Melton, 1983). Wolfe (1979) also argues that experiences of privacy are critical to the development of oneself as an independent person, to developing intimacy with others, and to maintaining relationships.

Increasing the decision-making autonomy of children may also create a climate in which children have a better understanding of their rights in general and are more likely to assert them. Melton (1983) reminds us that children's histories of being punished for failing to obey adults are likely to render them disbelieving of gestures designed to increased their autonomy. The probability of experiencing rights as applicable to oneself is even further decreased for children in care or custody who have rarely experienced this sense of entitlement to rights. The long-term political costs of systems where socialisation is based on experiences of 'law and order' morality rather than
democratic resolution and self-government, may be citizens who do not exercise their rights because they neither perceive themselves as having rights nor understand the application of rights. Thus one could argue that the initial step toward the effective use of rights, particularly for marginalized peoples such as children in care, are systems that foster genuine experiences of autonomy.

IV. The Law, Legal Remedies and Lived Reality: Key Discrepancies

The area of consent and confidentiality in health services for children continues to be a complicated and confusing area of law. This confusion is the result of having several pieces of legislation that deal with issues of consent and confidentiality, including the Health Care Consent Act, 1996 (HCCA), the Substitute Decisions Act, 1992 (SDA), the Public Hospitals Act (PHA), the Mental Health Act (MHA), and the Child and Family Services Act (CFSA). In addition, not all legislation has kept pace with Ontario’s consent law reforms. The lack of knowledge of consent law within the children’s services sector and the over-reliance on the CFSA has further contributed to the confusion.

1. Consent and Privacy Law in Canada and Ontario

While there have only been a few reported court decisions in Canada dealing with issues of consent to treatment for children, these cases have clearly stated that there is no age below which children cannot authorise their own care. Rather, the courts have found that where a child is a mature minor (i.e., able to understand the nature and consequences of treatment decisions) he or she should be able to make his or her own health-related decisions independent of a parent or guardian. During the 1990’s Ontario’s consent law was amended to bring it in line with Canadian common law, contemporary social science literature and emerging legal theory on consent and capacity. With one exception, the HCCA, the SDA and the MHA have all been amended to reflect the right of competent children to autonomous decision-making when it comes to their health care. The College of Physicians and Surgeons of Ontario’s policy #1-01, Consent to Medical Treatment, also reflects this position, stating that physicians may not assume a patient incapable just because of age.

In dealing with issues of consent, the HCCA, under sub-section 4(3), outlines the following legal principles. Patients should be presumed capable unless there are reasonable grounds to believe otherwise. A person who is capable of providing consent is also capable of withdrawing consent. In order for a consent to treatment to be valid, it must be related to the treatment, it must be informed, it must be given voluntarily, and it must not be obtained through misrepresentation or fraud. Finally, only health care

---


3 Subsection 21(1) of the HCCA limits the ability of competent children to plan for future situations where they may be found incompetent. This section states that where a person becomes incapable, a substitute decision-maker must follow wishes expressed while capable only if the wishes were expressed after sixteen years of age. Thus the expressed wishes of competent children under sixteen are not given the same weight as those of competent adults.
practitioners\(^4\) can make decisions regarding capacity. Thus, even if social workers or social service workers are acting in a clinical capacity, they do not have the legal authority to make determinations of competency with respect to treatment. However, under 1(b) of the Regulations of the *HCCA*, social workers may act as "evaluators" for the purpose of determining a person’s capacity with respect to an admission to a care facility. Furthermore, the capacity of a person with respect to receiving any personal assistance services\(^5\) may also be assessed by social workers.

As set out by the Supreme Court of Canada in *Starson v. Swayze*\(^6\), determinations of capacity involve two criteria. First, “a person must be able to understand the information that is relevant to making a treatment decision” and second, “a person must be able to appreciate the reasonably foreseeable consequences of the decision or lack of one”. This requires the person to have the cognitive ability to “possess retain and understand the relevant information”, to “apply the relevant information to his or her circumstances, and to be able to weigh the foreseeable risks and benefits of a decision or lack thereof.”

In *Starson*, the court explained that the application of the relevant information to a person’s own circumstance does not require that person to describe their condition as an “illness” or to “otherwise characterise the condition in negative terms”. The court held that a patient is also not required to “agree with the attending physician’s opinion regarding the cause of the condition”. However, if a patient, due to their condition is “unable to recognise that he is affected by its manifestations, he will be unable to apply the relevant information to his circumstances, and unable to appreciate the consequences of his decision”.

Furthermore, a person is not required to actually appreciate the reasonably foreseeable consequences of the treatment decision. The court stated that it is sufficient if the person has the ability to appreciate the consequences of a decision. This point is most relevant when considering the way in which health information has been presented to a child. For example, a child may have the ability to appreciate the consequences of a decision, but the attending health care professional may fail to adequately inform the child as to what those consequences are. Under these circumstances, a finding of incapacity would be unjustified.

Legal practitioners argue that the *CFSA* has not kept pace with changes in consent law. As a result there are a number of sections that continue to mislead those in the

---

\(^4\) Under the *HCCA*, health practitioners include members of the College of Chiropodists of Ontario, the College of Chiropractors of Ontario, the Royal College of Dental Surgeons of Ontario, the College of Dieticians of Ontario, the College of Massage Therapists of Ontario, the College of Nurses of Ontario, the College of Occupational Therapists of Ontario, the College of Optometrists of Ontario, the College of Physicians and Surgeons of Ontario, the College of Physiotherapists of Ontario, the College of Psychologists of Ontario, or a member of a category of persons prescribed by the regulations as health practitioners.

\(^5\) Under the *HCCA* “personal assistance service” means assistance with or supervision of hygiene, washing, dressing, grooming, eating, drinking, elimination, ambulation, positioning or any other routine activity of living, and includes a group of personal assistance services or a plan setting out personal assistance services to be provided to a person, but does not include anything prescribed by the regulations as not constituting a personal assistance service; (“service d'aide personnelle”)

children’s services sector who may not be otherwise trained in issues of consent. For example, section 28 of the CFSA states that “a service provider may provide a counselling service to a child who is twelve years of age or older with the child's consent, and no other person's consent is required...”. While it would appear that the purpose of this section at the time it was written was to ensure that service providers felt confident in providing counselling services to children twelve and over in the absence of additional consent, in practice this section has been interpreted as negating the rights of those under 12 to autonomous decision-making with respect to counselling. In fact, it appears that the reference to age twelve in this section is frequently used by service providers as the presumptive age of capacity for all treatment decisions.

Section 132 of the CFSA is also misleading to those in the children’s services sector. This section states that “a service provider shall not administer or permit the administration of a psychotropic drug to a child in the service provider’s care without, a) if the child is sixteen years of age or more, the child’s consent; or b) if the child is less than sixteen years of age, the consent of the child’s parent or... [guardian]”. Because the HCCA takes precedence over the CFSA, section 132 has been nullified. Nonetheless, this section continues to be widely used by the children’s services sector as a framework for the administration of psychotropic drugs.

Section 107 of the CFSA is also problematic. This section states that “a child in care has a right to be consulted and to express his or her views, to the extent that is practical given the child's level of understanding, whenever significant decisions concerning the child are made, including decisions with respect to medical treatment...”. The problem with this section is that it may lead service providers not trained in the law of consent to presume that mere consultation is sufficient even for a capable child.

Similar to consent law, the disclosure of health-related information is a complex and developing area of law. While a full discussion is beyond the scope of this paper, it is important to note that Children’s Aid Societies (CAS’s) and children’s residential facilities currently operate in a legislative vacuum when it comes to the disclosure of children’s health information. Neither the provincial Freedom of Information and Protection of Privacy Act nor the Municipal Freedom of Information and Protection of Privacy Act apply to CAS’s or residential facilities. While Part VIII of the CFSA deals with the disclosure of personal records by service providers, this section has never been proclaimed in law. Before being proclaimed, Part VIII ought to be reviewed and revised in light of the current legal climate and legislative changes that have occurred in Ontario’s consent law in the last decade. In the absence of legislative certainty about the disclosure of health information, inconsistent and variable policies and procedures have been developed by CAS’s and children’s residential facilities across the province.

---

7 According to Regulation 70, s. 49 of the CFSA psychotropic drugs include anti-psychotic, anti-depressant, sedative, hypnotic, anti-anxiety, anti-hyperkinetic, and anti-manic drugs.
8 The province of Ontario released a draft Privacy of Personal Information Act (PPIA) in February 2002. The draft PPIA, 2002, would apply to the collection, use and disclosure of personal information by an organisation subject to provincial jurisdiction, possibly including Children’s Aid Societies and children’s residential facilities.
For medical practitioners there is greater clarity in the area of disclosure of medical information. Regulation 856/93 of the *Medicine Act* states that the disclosure of information about a patient may constitute an act of professional misconduct. There is nothing in the *Medicine Act* or Ontario’s consent law that excludes competent children from this entitlement to confidentiality. Further, the College of Physicians and Surgeons of Ontario’s policy #9-00, *Confidentiality and Access to Patient Information*, states that the framework for establishing consent for the disclosure of health-related information is based on the framework for obtaining consent to treatment (i.e., the physician must determine if the patient has the capacity to consent). Thus where children have the competence to consent to treatment, the disclosure of health-related information without the child’s consent may constitute a breach of the physician’s duty of confidentiality (Rozovsky, 1992).

2. Legal Remedies for Children
The Consent and Capacity Board (CCB) is the main avenue available in Ontario for addressing decisions regarding consent to treatment. The CCB is an independent, provincial body that conducts hearings under the *MHA*, the *HCCA*, the *SDA* and the *Long Term Care Act*. CCB members are psychiatrists, lawyers, and members of the general public. Under subsection 32(1) of the *HCCA*, any person found incapable can apply to the CCB for a review of a finding of incapacity. Thus, the CCB process can deal with decisions with respect to capacity that are made by a health care practitioner in any setting, including group homes, foster homes, residential care facilities, and custody facilities. Where children disagree with a decision made by the CCB, they can appeal that decision to the Superior Court of Justice.

Although the CCB rarely receives requests for hearings from children, some legal practitioners with CCB experience say that the process is relatively accessible to children. The CCB process can be initiated by faxing a Form A application under the *HCCA* to the CCB (see attachment). Under the *HCCA* the hearing must commence within seven days of the request. Most children will qualify for legal aid for this process and the Board, under subsection 81(1) of the *HCCA* can direct the Office of the Children’s Lawyer to appoint a lawyer where a child appears before the CCB without counsel. Furthermore, under subsection 81(2) of the *HCCA* assessments of incapacity with respect to medical treatment do not deem individuals incapable of directing their counsel. Thus for the purposes of the CCB process, children can expect their counsel

---

9 Children also have the option of filing a civil action for assault where they feel treatment has been imposed on them without their consent. Legal practitioners argue that while civil cases may strengthen the rights of children in general, the cumbersome and adversarial nature of the civil system may prevent it from being a feasible avenue for children. Where there are concerns that a medical practitioner has failed to assess capacity to consent to treatment or to secure informed consent, a complaint may also be filed with the College of Physicians and Surgeons of Ontario (College). In some circumstances the OCFSA may be able to file a complaint on behalf of children. In one such case, the Complaints Committee of the College found that the physician had failed to provide adequate care to the youth. In reaching this conclusion, it relied on findings, among others, that the doctor had failed to assess the youth for capacity to consent and failed to discuss with him or a substitute decision maker the regimen prescribed. These failings with respect to the consent process contributed to the decision of the Complaints Committee to refer the case to the Quality Assurance Committee of the College.

10 The OCFSA was advised by John Harper, the present Chair of the Consent Capacity Board, that only one application for a review had been submitted by a minor to the CCB in the past eight years.
to act in accordance with their wishes even if there are outstanding questions regarding their capacity.

At the CCB hearing, each party may call witnesses and enter documentation. Children have a right to attend the hearing, although they are not required to do so. While children may be intimidated by the idea of a CCB hearing, legal practitioners say that applicants generally find the hearing to be a positive experience since the onus is on the medical practitioner to justify a finding of incapacity. However, children can request that particular measures be taken to ensure that they feel comfortable at the hearing, including the removal of observers.

Currently, there exists a statutory requirement that attending physicians must inform persons 14 years of age or older in a psychiatric facility who have been found incapable of their rights to apply to the CCB. Furthermore, section 17 of the HCCA requires health care providers to comply with the standards set out by their professional college to inform the person about the consequences of a finding of incapacity, which may include the right to apply to the CCB for a review of the finding. For example, the standards set out by the College of Physicians and Surgeons requires health care providers to inform patients of a finding of incapacity, of intentions to seek substitute consent, and of the patient’s right to apply to the CCB to have a finding of incapacity assessed regardless of age. The guidelines also require that medical practitioners provide patients with assistance applying to the CCB. In reality, legal practitioners agree that children are seldom advised of their right to apply to the CCB and service providers in the children’s services sector are generally not aware of the remedies available through the CCB.

Legal practitioners also argue that CAS workers are not likely to advise children of their right to apply to the CCB since they are likely to be named as the substitute decision-maker in findings of incapacity. This role may impair their ability to assist children in applying to the CCB since they may be oriented towards informing themselves of treatment options and making critical medical decisions under perceived or real time constraints instead. Concerns of the liabilities that may arise if treatment is delayed may also add to their reluctance to advise children of their right to apply to the board.

---

11 Regulation 741, subsection 15(1) of the MHA states: if a person who has been admitted to a psychiatric facility as a patient is 14 years old or older and if the person's attending physician proposes treatment of a mental disorder of the person and finds that the person is incapable with respect to the treatment within the meaning of the Health Care Consent Act, 1996, the attending physician shall ensure that, (b) a rights adviser is promptly notified of the finding of incapacity. Under subsection 15(2), a rights adviser who is notified of a finding of incapacity shall promptly meet with the person who has been found incapable and shall explain to the person the significance of the finding and the right to apply to the Board under the Health Care Consent Act, 1996 for a review of the finding. Under 15(4) the rights advisor is also responsible for assisting the person who has been found incapable in applying to the Board and in obtaining legal services.
Few formal avenues exist for children who feel that their health information has been disclosed inappropriately. Where a health care practitioner has breached confidentiality, children can file a complaint with the College of Physicians and Surgeons of Ontario, or another relevant College. For complaints that a CAS worker or residential facility staff has inappropriately disclosed information, children must trigger the internal complaint procedure of the agency or facility. However, lengthy complaint procedures may not be the best avenue for addressing time-sensitive situations involving the potential disclosure of information. Finally, children have the option of pursuing a civil remedy through the courts, yet the potential costs and delays associated with this option also render it prohibitive for most youth.

3. The Experiences and Concerns of Youth in Care

While several of the youth consulted in this project spoke about having positive health care experiences in the children’s services sector, the overwhelming majority felt that while in the care system they had little control over their health, were denied crucial information about their health status, had little privacy when it came to health information and had difficulty advocating for themselves on health-related matters. The youth also raised concerns about poor staff/youth relations in the care system and discussed the difficulty finding advocates to assist them in asserting their rights to autonomous decision-making.

Nearly all of the youth consulted reported that decisions regarding their health were generally made by the adults in their lives. They said that health decisions were made by some combination of their social worker, health care practitioner, foster parents, and residential care staff. In fact, many youth reported that they rarely received information regarding their health directly from a health care practitioner. Excluding youth from information sharing and decision-making is particularly problematic given that many of the youth had concerns about the extent to which their behaviours were pathologized by staff. One youth said, “if you see the way they write about kids in care in the staff shift log, you’d think we need all that medication”. The youth also reported having little say in selecting their medical practitioners and said that their complaints about practitioners were not always taken seriously.

Many of the youth also felt that requests to take control of their own health were not taken seriously. For example, requests for treatment were frequently denied, particularly when older youth requested counselling services. Several of the young women were also concerned that they did not have control over their sexual health while living in residential facilities since their oral contraceptives were administered by the facility staff. These youth said that ultimately they had to stop using oral contraceptives because staff often administered them at different times of the day and medications were not available when residents went AWOL or went home for planned visits.

Many of the youth also reported being coerced into complying with chemical treatment regimes while in foster homes or residential care facilities. According to one youth “when you were younger you weren’t even told what you were taking-- when you were
older you would be told what it was, but still forced to take it". Another youth said that residential facility staff would say "if you want to stay on program, take your medication". A number of youth also said that they were frequently consequenced for failing to comply with medication regimes, including “locking down the entire unit until the residents have all taken their medication”. Several youth also felt that they were "over medicated" in residential care facilities. One youth said that despite protesting, she was “completely sedated much of the time”. She goes on to say:

“I had to get a court order to get my prescription revoked. Since I was taking so much medication it took another two years to get off all of it. So many years of my life were ruined because of over-medication. I wish you [OCFSA] had of come.”

Many of the youth also reported having little or no information regarding the health services they received, especially when it came to the administration of medication. According to one youth “I didn’t know why I was taking my medication. They just gave me my medicine.” One youth said “I didn’t even know I was taking Ritalin”. Many of the youth also remember being required to undergo assessments or treatment “when they were little”. However, a number of them did not understand why they went and “have no idea what the result was”.

The youth also said that while some facilities were good at protecting the privacy of residents, their health information was not always kept confidential and they rarely had a say in who accessed their information. One youth said “when I went to the doctor it was always implied that my foster parents and social worker would know. As far as I knew I had no choice.” Another youth said that one residential facility disclosed confidential mental health information to the other residents. Another youth was concerned that her foster family disclosed her personal medical information “to their friends, aunts and cousins”.

Many of the youth did not have the close, respectful and lasting relationships with staff that would be required to engage in consent as a process. Youth felt that staff focused on “punishing kids” and did not always listen to, work with, or “care about” children. For example, several of the youth said staff “just do the bare minimum” and “don’t pay attention to children, just the file”. Another youth said “the staff said they were ordered to show no feelings about any of us. They are not supposed to care for us. They go home and don’t think about us.” Some of the youth also felt that staff should act “more professionally” and should be “more educated” about the issues facing children in the care system.

Many of the youth also spoke about the difficulty finding someone to advocate for them when they were unable to advocate for themselves. Several of the youth felt that CAS workers were not always available to advocate for them and residential facility staff were not always willing or able to play this role. The youth also said that they often had difficulty contacting the OCFSA to get support in making their own health decisions. One youth said “in reality we are not allowed to use the phone to get staff in shit or they tell us to wait to call the Advocacy Office.” Another youth said “the phone is in the staff
office and the office is always locked.” Several of the youth talked about “wishing that the Advocacy Office had come to see what was happening” in their residential care facilities. It is recommended that the OCFSA play a greater role in assisting youth with advocating for their right to be heard around health decisions, and that service providers facilitate this process.

V. Moving Towards Critical and Ethical Understandings of Consent and Confidentiality: Some Essential Principles

From this consultation process a number of essential principles have emerged that should guide the work of the OFCSA as it advocates for children in the care system around issues of consent and confidentiality. These principles include: ensuring autonomous decision-making, presuming capacity, properly assessing capacity, developing capacity in children, understanding consent as a process, obtaining valid consent, and ensuring that children are provided with confidential health services. Given the current status of consent law in Ontario and Canada, contemporary theory on consent and confidentiality, and the concerns expressed by children in the care system, it is reasonable to suggest that the children’s services sector should be held accountable to this framework.

1. Presumption of capacity
As indicated in the HCCA, children should be presumed capable of consenting unless there are reasonable grounds to believe otherwise. Children should not be presumed incapable simply because of age, disability, or the administration of psychotropic drugs, although such factors may be relevant in the assessment of capacity. Only the medical practitioners identified in the HCCA should make determinations of competency, with the burden of proof falling on these practitioners to demonstrate, where appropriate, that the child should not be permitted to make health-related decisions.

2. Autonomous decision-making
Children have the right to be heard on matters concerning their health and to make their own health decisions. Children who are determined not to be competent to make their own health decisions should still have the opportunity to participate in treatment decisions and to be taken seriously on matters concerning their health. This does not mean that parents, caregivers and service providers should not play a role in competent children’s health-related decisions. Rather they have an obligation to ensure that all children are supported and assisted while health decisions are being made and to ensure that children’s rights to self-determination, personal dignity and integrity of the self are respected. This enabling role must include advising children of their right to have findings of incapacity reviewed by the CCB.

3. Assessing capacity
As stated supra, determinations of capacity should be based on the ability of the person to understand the information that is relevant to the treatment decision and to appreciate the reasonably foreseeable consequences of the decision or lack of one.
Competence should not be viewed as a fixed characteristic of the person but should be based on the social maturity and the developmental ability of the child at the time of the decision and on the nature of the treatment decision itself. Therefore, a child could be competent to consent to one treatment but not to another or competent at one point but not at another.

4. Developing capacity
Children must be given the opportunities and assistance they need to develop their competence to make health decisions. Competence can be developed by providing children with progressively more responsibility for their lives and health. This could include:

- gradually and appropriately escalating the child’s involvement in treatment decisions
- offering increasing responsibility for treatment compliance
- helping the child to articulate preferences for how the treatment is administered
- assisting the child to develop and implement coping strategies
- providing opportunities to ask and answer questions during health appointments
- including the child in problem-solving discussions
- developing attributes such as self-worth and a sense of entitlement
- developing skills that enable children to participate in decision-making, such as using feeling words, asking for what one wants, and saying no
- supporting children during periods of emotional and physical stress to reduce anxiety, isolation and loneliness

5. Consent as a process
Consent should be conceptualised as an ongoing process rather than an isolated event. The consent process will overlap and interact with assessments of capacity. A good consent process involves an ongoing and active dialogue between the child, medical practitioner and, in some cases, the guardian or another adult. The ideal dialogue allows all involved parties to consult one another, share fears, concerns and information, and invite and respond to each other’s ideas. Thus consent as a process goes well beyond signing a consent form or providing any one piece of information. The development of strong, trusting, interpersonal and professional relationships between the child, guardian and medical practitioner are critical to engaging in consent as a process. In some cases, it may be necessary to facilitate the development of new relationships where existing relationships are curtailing the consent process.

6. Valid consent
As per the HCCA, valid consent must be informed, related to the treatment, voluntary, and free from misrepresentation or fraud.

Informed consent
Information is a critical component of the consent process. When making or participating in health decisions, children should receive information about the nature of the available treatments, the goals of treatments, their expected benefits, the common
and serious risks, the material side effects, and the likely consequences of not engaging in particular treatments. Children should also be informed of the history and effectiveness of treatment options. Children should have the opportunity to engage in private, confidential discussions with physicians and should be encouraged to discuss treatment decisions with other trusted persons. After receiving information, children should be afforded ample opportunity to reflect on their health situation in the context of their own value systems. Where guardians are involved in the treatment decision, they should have adequate information about the nature and consequences of treatment decisions in order to support the child. Finally, children should be made aware that it is permissible and often advisable to seek a second medical opinion to help with informed consent decisions.

In order for children to participate in the consent process, health information must be provided in a way that corresponds to the child’s experience and developmental level. Technical or interpretative language must be translated for the child. Special attention must also be paid to the meanings of the words being used and to the issues that are most pressing at the time for the child. Service providers must also ensure that when providing information in an accessible format they do not compromise the child’s right to receive comprehensive and accurate information. In order to account for different literacy levels, several modalities should be used to convey health information (e.g., verbal, audio-visual, written). In all cases, children should be encouraged to ask questions. Once treatment has commenced, regular reviews of treatment progress should be conducted and children should be provided with adequate information about the progress in order to provide ongoing informed consent.

Where consent is being obtained from a child who speaks English as a second language or who is using sign language, it is important to remember that one’s command of the language depends on the subject being discussed, the circumstances of the discussion and the dialect of the person. Further, individuals may be able to speak in a social context but may not understand health-related information. Further, individuals may not readily admit that they are having difficulty grasping the full meaning of the health information. Where there are any doubts that the child is not understanding the information, arrangements should be made for a translator. When using a translator the information must be conveyed at a level that is comprehensible to an interpreter and translated at the same level to the child. Where the information is of a sensitive or private nature, especially where sexual health is involved, special attention should also be paid to the appropriateness of the translator. Further, translators must be available throughout the time that the child is receiving the services to enable the child to engage in consent as a process and to assist them should they wish to alter their consent.

Consent is related to a treatment
Consents should be specific to the procedure being performed. Children should not be required to provide ‘blanket consents’ for all medical care and guardians who are acting as substitute decision-makers should never provide these consents on behalf of children.
**Voluntary consent**
In order for consent to be valid it must be free of undue influence and coercion. However, voluntary consent can be particularly difficult to receive from children in the care system who are vulnerable to both overt and covert coercion. Overt coercion includes threats of being consequenced or removed from a program for failing to consent to treatment. Covert coercion can also occur in the care system since children may be used to adhering to rules and requirements, may be used to decisions being made for them, may have fears of reprisal or may have concerns about alienating caregivers who have power and influence over their lives. Caregivers and physicians must be knowledgeable of these dynamics when securing valid consent and must work to address this power imbalance.

**Absence of misrepresentation or fraud**
In order for consent to be valid there must be no misrepresentation of material information. This means that health care practitioners and guardians should not withhold details or present them in such a way that it serves to mislead the child and results in a consent that the child would otherwise decline. While not always intentional, these material omissions can be common in consents to psychotherapy and drug treatment.

**7. Confidential health services**
The principles informing the disclosure of health information should be the same as those for consent to treatment. Thus, where a child is considered competent, they should be entitled to the same guarantees of confidentiality as adults. As such, competent children’s confidences must be respected whether or not the adults in their lives agree with their decisions or their assessment of their own best interests. For children who are not considered competent, ideally a disclosure plan should be developed by the medical practitioner outlining how the child wishes the information to be disclosed. From the outset, health care practitioners, service providers and guardians should inform children about the requirement of confidentiality, including full explanations of what confidentiality entails and the conditions under which confidentiality might be breached. This information should be conveyed in an accessible manner, using examples for clarification. CAS workers who obtain information while providing supportive counselling must be particularly clear about the information they will be required to disclose.

For children in the care system, issues of confidentiality are complicated by legal mandates to protect children and obligations to provide supportive services. Issues of confidentiality are also complicated by the presence of multiple caregivers, including staff at residential care facilities, custody facilities and Children’s Aid Societies, who may need to access children’s medical information in order to protect children from harming themselves or others or to provide appropriate support for children with complex needs. To ensure that confidentiality is not subject to individual discretion, confidentiality policies should be developed by children’s services agencies. The Office of Child and Family Service Advocacy is recommending that children’s service agencies and providers develop uniform privacy and access to information policies based upon
the ten principles of the *Canadian Standards Association’s Model Code for the Protection of Personal Information* attached. These policies should include guidelines for handling medical records and for including medical information in case files. Confidentiality policies should also be clearly communicated to children.

November 2003
References


