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**The Best Interests of Adults with Intellectual Disabilities:
Are There Adequate Legal Safeguards?**

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Introduction

The *Canadian Charter of Rights and Freedoms, 1981* guarantees fundamental freedoms and legal rights to all citizens. These rights include the right to life, liberty and security of person and the right not to be deprived thereof except in accordance with the principles of fundamental justice. The right not to be arbitrarily detained or imprisoned and the right not to be subjected to any cruel or unusual treatment or punishment are also stated in the *Charter*. Persons with mental and physical disabilities are considered equal before and under the law without discrimination. However, for some persons with a severe intellectual disability the right to liberty may be in conflict with the right to security of person. This paper explores the laws and regulations which apply to persons with intellectual disabilities in the province of Ontario with specific attention to the issues of consent and substitute decision making. It is postulated that the current legislation is inadequate to safeguard the rights of some vulnerable adults. As the Government of Ontario transforms the developmental disability service sector, it is timely to ascertain that the intent of the laws and regulations are applicable to the new paradigms of inclusion and community-based care.

Population of Concern

Vulnerable citizens include children, the elderly and persons with intellectual, psychiatric or physical disabilities. The focus of this paper will be adults with intellectual disabilities (ID)¹ who live in the province of Ontario. By definition, these are adults who have limited intelligence and are unable to function in two or more areas of independent living. They have had these disabilities before the age of eighteen and their disabilities are considered permanent and, although there is a capacity for limited new learning, the level of intelligence is considered static. The implications of these characteristics will be discussed as we review the pertinent acts related to consent and substitute decision making.

Although some parallels can be made with older citizens and with persons who have psychiatric or physical disabilities, distinct differences exist. People with physical disabilities have made many gains in order to ensure that their competent voices are heard. Seniors are capable of making advanced directives prior to the time when they may need relatives to make decisions on their behalf. Similarly, psychiatric patients can direct, in advance, their choice of treatment and designate their power of attorney. When in hospital or on Community Treatment Orders, patients with psychiatric disorders have access to Rights Advisors and to Capacity and Consent Review Boards. If found not competent to stand trial or not guilty due to a mental illness, those before the courts have access to the Ontario Review Board on a regular basis. There is the expectation that perhaps at a future date they will be competent. This is not assumed possible for someone with an intellectual disability as there still remains the assumption that persons with a moderate to profound intellectual disability are globally and persistently incompetent.

The main concern for this population has been the identification of a substitute decision maker. There is no legal process of routine external review for persons with ID who are living within institutions and other settings managed or funded by the Developmental Services Branch of the Ministry of Community and Social Services. Unlike persons with a psychiatric disorder who are protected by the *Mental Health Act*, 1990, (Government of Ontario, 1990) persons with ID may be detained and/or restrained for extended periods of time without access to a review process. Although the intent is to maintain the safety of the person and the safety of others, it is not clear whether the detention is arbitrary or not. Current legislation in Ontario and its implementation have created some injustices for some persons with ID and these areas of concern will be highlighted using specific examples from case law as well as a recent ruling from the Consent and Capacity Review Board.

Health Care Consent Act, 1996

The *Health Care Consent Act*, 1996 is an Ontario Act which provides rules with respect to consent to treatment in health settings. It is designed to facilitate treatment, admission to care facilities, and personal assistance services, for persons lacking the capacity to make decisions about such matters. In addition, it is designed to promote communication and understanding between health practitioners and their patients and to ensure a significant role for supportive family members when a person lacks the capacity to make decisions. The Office of the Public Guardian and Trustee is permitted to intervene only as a last resort in decisions on behalf of

¹ There are three criteria needed in order to make a diagnosis of Intellectual Disability or Mental Retardation: 1) An individual has sub average intellectual functioning on an IQ test; 2) he/she has concurrent deficits or impairments in present adaptive functioning in at least two areas such as communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health and safety; and 3) the onset of the disability is before the age of 18 years. (DSM-IV-TR, 2000)

incapable persons concerning treatment, admission to a care facility or personal assistance services. (Government of Ontario, 1996)

How this Act applies to persons with ID relies on the interpretation of some key concepts such as the capacity to make decisions and what constitutes a “treatment”. The capacity to make decisions is a function of the individual in question and is dependent on a particular choice at a particular time. For instance, even someone with a profound intellectual disability may be able to decide whether he wants to eat his potatoes rather than the peas on his plate. This of course is not a treatment decision and may appear trivial in the eyes of the law but for the psychological well being of persons with ID it is fundamentally important that they be given the freedom to choose as much in their lives as they are capable of doing. It is this lack of freedom to choose in small things that constitutes one aspect of institutional abuse. (Goffman, 1961)

The usual criteria for competence to consent to medical treatment includes the ability to understand the medical problem, the ability to understand the proposed treatment, the ability to understand the alternatives to the proposed treatment, the ability to understand the option of refusing treatment and the ability to appreciate the accepting or refusing the proposed treatment. Consents must be given voluntarily, be informed, related to the treatment and not obtained through misrepresentation or fraud. (Health Care Consent Act, 1996, s. 11) Informed consent means that the practitioner proposing the treatment has taken the time to explain the treatment, its risks and the alternatives, as well as the consequences of non treatment. Thus, informed consent is a dialogue and the practitioner has the responsibility to inform the patient in a manner that facilitates understanding. Persons who are deaf or who do not speak the same language as the practitioner are not considered incompetent and interpreter services are provided. Similarly information can be given at an educational level which is understandable by persons with less education than the practitioner. Many persons with mild and even moderate intellectual disabilities can understand and appreciate simple treatment procedures such as a flu shot or a cast for a broken ankle. Ideally, the assessment of capacity to participate in the process of giving consent should be individualized and reassessed for each specific intended treatment.

The *Health Care Consent Act, 1996* is intended to facilitate treatment, admission to care facilities, and personal assistance services, for persons lacking the capacity to make decisions about such matters. Persons are presumed to be capable unless there is reason to believe otherwise. If the practitioner is of the opinion that the person is incapable with respect to treatment, the *Health Care Consent Act, 1996* s. 10 names the substitute decision maker as the person who gives consent on behalf of the individual. This is usually the next of kin, or if no relative is available, the Public Guardian is permitted to intervene to make a decision concerning a proposed treatment. This is relatively straightforward for most medical treatments such as surgery, medication for specific illnesses, vaccinations, etc. There are areas which are more problematic and open to interpretation by different parties. A closer look at the *Substitute Decisions Act, 1992* will reveal the areas of concern for persons with intellectual disabilities.

Substitute Decisions Act, 1992

The *Substitute Decisions Act, 1992* gives the duly designated substitute decision maker the ability to consent on behalf of a person who is deemed incapable of giving consent. This includes decisions related to treatment, admission to care facilities and to personal assistance services. As defined by the *Health Care Consent Act, 1996*, “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.

The *Substitute Decision Act*, 1992 makes a distinction between spouses, partners and other family members who are not authorized to act in the personal care area apart from treatment, admission, and personal assistance services under the *Health Care Consent Act*, 1996, unless the family member is formally appointed as guardian or attorney. In this way, personal care matters outside the *Health Care Consent Act*, 1996 become problematic. There is a gap in the two legislations that occurs when a person with ID who lacks the capacity to give consent and resides in a facility covered by the *Developmental Services Act*, 1990. Unless the relative has been formally appointed as guardian there may be confusion as to the areas in which they can or cannot give consent. The Public Guardians Office is very clear on the limits of consent and restricts their interest to very narrowly defined health care issues. This interpretation of the legislation leaves persons whose substitute decision maker is the Public Guardian vulnerable as there is no one who can give consent for personal assistance and other activities such as swimming, bus trips, etc.

Within the *Substitutes Decision Act*, 1992 there are limits on the guardian's areas of consent. It is clearly stated that the guardian shall not use confinement or monitoring devices or restrain the person physically or by means of drugs, and shall not give consent on the person's behalf to the use of confinement, monitoring devices or means of restraint, unless the practice is essential to prevent serious bodily harm to the person or to others, or allows the person greater freedom or enjoyment. Electric shock as aversive conditioning can only be consented to in accordance with the *Health Care Consent Act*, 1996.

Regulation 272 of the *Developmental Services Act*, 1990 outlines the use of restraints within group home staff-supported residential accommodations. The regulation is intended to define the procedures when it is the common law duty of a caregiver to restrain or confine a person when immediate action is necessary to prevent serious bodily harm to the person or to others. The regulation is very specific in that it states "for greater certainty, physical restraint does not include,

- a) restriction of movement, physical redirection or physical prompting, unless the restriction of movement, physical redirection or physical prompting is brief, gentle and part of a behaviour teaching program: or
- b) the use of helmets, protective mitts or other equipment to prevent a resident from physically injuring or further injuring himself or herself." (*Developmental Services Act* – R.R.O.1990, Reg.272) There is mandatory reporting to the Ministry of Community and Social Services each time restraints are used.

The *Developmental Services Act*, 1990 does not address consent issues for the use of the restriction of movement as part of a behaviour teaching program. For the most part family members are the substitute decision makers for individuals with ID living in facilities governed by the *Developmental Services Act*, 1990. It is not clear whether they are in fact permitted to give consent to the use of restriction of movement as part of a behavioural support plan. **One call to the Public Guardian for permission to use time out periods as part of a behavioural support plan resulted in the response that *behavioural support plans were not medical***

treatments and therefore the Public Guardian did not have any role in the decision making.²

The use of psychotropic medication to assist in the management of aggressive and potentially injurious behaviour is controversial (Radouco-Thomas et al, 2004) but could be seen as allowing the person greater freedom or enjoyment as otherwise he may need to be hospitalized or placed in a more restrictive environment. In community and institutional settings, there is a risk that medication will be used as substitute for adequate staffing. Although the intent of the *Substitute Decisions Act*, 1992 is to foster independence while choosing the least restrictive and intrusive course of action, there is the potential to make consent easier to obtain for medical treatment (psychotropic medication) than it is to obtain consent for the treatment plans created by psychologists. These plans often require a change of behaviour on the part of the direct care worker and there may be a tendency for the direct care worker to prefer that the person with ID be medicated rather than invest the energy in the implementation of a behavioural support plan.

Twice I have called the Public Guardian to obtain permission to change a psychotropic medication which a family physician has been prescribing for some time. Although these were active files with the Public Guardian and consent had been given recently for flu shots and dental extractions, the Public Guardian was unaware that either patient was being prescribed a psychotropic medication. Although the College of Physicians and Surgeons of Ontario³ advises that consent must be obtained, there is little incentive for busy physicians, who are being paid on a fee for service, to take the time to call the Public Guardian.

It would be easy to blame the physicians and other professionals as the onus is on the practitioner to make a decision as to whether someone is competent to understand and give consent to a treatment or procedure. If the practitioner does not think the person is competent, then it is his/her responsibility to find the appropriate substitute decision maker prior to initiating the treatment. If the practitioner does not do this, he can be found guilty of assault or battery. (R. v. Wiens, 1984⁴, Malette v. Schulman et al⁵) He could be found guilty of professional misconduct.

Without it being intended, there are many way physicians unwittingly participate in abuse and neglect of persons with intellectual disabilities (ID). (Ryan et al, 2001) In Ryan's survey, physicians may have been asked to approve the use of behavioural strategies that are inconsistent with regulations, and thereby take responsibility for the deviation from policy. Physicians may have assumed that social service agencies were providing oversight and therefore there was little risk of abuse. Physicians may have been asked to 'explain away', in writing, obvious signs of abuse, without adequate investigations into these signs. Because the majority of parents and providers are adequate to excellent, some physicians made the

² The author has extensive clinical experience with persons with ID and psychiatric disorders and clinically has found that although the office of the Public Guardian and Trustee is very accessible and helpful in matters of medical treatment, it does not give opinions in the areas of admission to facilities or of personal assistance services. In addition, their definition of treatment does not include behavioural therapies or counseling. They restrict their consents to medications, surgery, dental care, radiological tests and recently they gave permission for genetic testing as it would have treatment implications if positive for a genetic disorder.

³ Consent to Medical Treatment, CPSO policy, <http://www.cpso.on.ca/Policies/consent.htm> (Accessed July 2, 2006)

⁴ This case is described in *Physician Heal Thyself: The Rights of the Patient* (1985) by Allan Gould http://www.allangould.com/magazines/somefavourites/physicianhealthysself/magazines_somefavourites_physicianhealthysself.htm (Accessed July 2, 2006)

⁵ MPA 878 Legal Aspects of Health Care (2006) Volume 1, pg.142.

assumption that ALL of these providers were appropriate and trustworthy. If the provider had been in business for a long time this was especially noticeable. That is, although the evidence suggested that abusers will continue to abuse for as long as they can get away with it, some physicians still believed that many years experience in the field made the provider somehow less suspect. The physicians in the sample appeared unaware of the presence or procedures to access the entire science of positive behaviour supports which provides extensive education and training, and if appropriately used, may make the use of physical restraints, seclusion, and chemical restraints unnecessary. (Ryan et al, 2001)

No one is stating that there is a deliberate policy to overmedicate or abuse persons with ID however, there are systemic patterns that reinforce the excessive use of psychotropic medication. These include: understaffing, lack of knowledge, lack of monitoring, an unwillingness to reduce medications when the situation is stable, the lack of crisis facilities, including psychiatric inpatient beds, and perhaps, the maintenance of a strictly medical treatment model within the Public Guardians Office. Complex and confusing legislation adds to the difficulties. In order to reduce the use of chemical and physical restraint and to limit the potential for abuse, it is important to examine all the factors that influence the physician to actually write the order for a psychotropic medication. Without examining and altering sections of the system which are problematic, it is likely that the most conscientious physicians will merely find it too difficult to care for this group of complex, needy and vulnerable patients. As the burden of conscience is borne by the ethical professional, it may be that professionals will focus on patients who are less challenging and avoid treating patients who are living in facilities funded under the *Developmental Services Act*.

It is also unclear **how the *Developmental Services Act, 1990* relates to the *Health Care Consent Act, 1996*, *Substitute Decisions Act, 1992* and the *Mental Health Act, 1990***. The *Developmental Services Act* applies to group homes and institutions funded through the Ministry of Community and Social Services (MCSS). The *Health Care Consent Act* indicates that it applies to persons in approved facilities under the *Public Hospitals Act*, the *Mental Hospitals Act*, the *Private Hospitals Act*, the *Charitable Institutions Act*, the *Homes for the Aged and Rest Homes Act* and the *Nursing Home Act*. Is there a reason that facilities and homes under the *Developmental Services Act* were left out? Presumably the main reason is that the previous acts are under the Ministry of Health and Long Term Care and the *Developmental Services Act* applies to facilities who receive their funding from the Ministry of Community and Social Services. One would hope though that such an important concept as consent to health care, including personal assistance service, would have particular relevance to the vulnerable persons with ID. The *Developmental Services Act* alone does not adequately protect these individuals who are living in homes and facilities funded by the Ministry of Community and Social Services.

The MCSS is in the process of transformation. In the future it will be less involved in the direct delivery of service and will be more focused on ensuring and enhancing the quality and accessibility of services to persons with ID. (Ministry of Community and Social Services, 2006) This means the Ministry will need to develop processes to evaluate the programs delivered by transfer payment agencies and ensure there is accountability within the system. (Sossin, 2003) As more funds are directed towards individualized funding, there will be more opportunity for families to purchase services from private providers, including for profit service providers, and the Ministry's ability to monitor and regulate standards will decrease. Therefore, it will be even more important that the legal protection for ensuring informed consent by a legal substitute decision maker is expanded and applied wherever an individual is receiving treatment, care and

support. Equally important is an independent review process for persons whose freedom is being restricted in community settings.

Consents for Research, Sterilization and Transplantation

Both the *Health Care Consent Act* and the *Substitute Decisions Act* specifically mention that guardians must follow the law relating to giving or refusing consent on another person's behalf to a procedure whose primary purpose is research, and guardians must also follow the laws regarding sterilization and transplants. Persons with intellectual disabilities have been subjected to abuse and discrimination in the past. (Cole, 2001) The Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans (Government of Canada, 1998) states:

Ethical considerations around research involving those who are not competent to give a free and informed consent on their own behalf, must seek to balance (1) the vulnerability that arises from their incompetence with (2) the injustice that would arise from the exclusion from the benefits of research. (2.9)

Thoughtful ethicists and researchers have identified that without some research on specific issues concerning persons with ID we are doing them a disservice as we continue to use treatments and programs which have not been adequately assessed for this population. (Weisstub & Arboleda-Flórez, 1997) It may be that the research proposal involves assessing current therapies and is intended to ascertain whether they are effective. It is often easier to be overly protective than to assess the merits of any given research proposal. (Lai et al, 2006)

The classic case of **E. (Mrs.) v. Eve (1986)** outlines the issues related to consent for sterilization that resulted in a Supreme Court Ruling which is often repeated. Essentially Eve was deemed incompetent under the *Mental Health Act* of Prince Edward Island and her mother was considered the substitute decision maker. The mother gave consent for sterilization because she did not want to be responsible for the care of a potential grandchild. Initially, the request for sterilization was denied and an appeal was launched to the Supreme Court of Prince Edward Island. The Official Trustee was appointed the Guardian, but the Court permitted the exercise of the *parens patriae* jurisdiction (where courts have the right to make unfettered decisions concerning people who are not able to take care of themselves) to authorize the sterilization. Although initially Mrs. E. requested a tubal ligation for her daughter, Eve underwent a hysterectomy. The Guardian appealed the decision to the Supreme Court of Canada which ruled that the principle of *parens patriae* did not apply, essentially because the original request for sterilization came at the request of the mother for her own interests rather than the best interests of Eve. The judgment stated that incompetent persons should have independent representation before the court. The appeal was upheld.

This ruling has been used repeatedly to deny women with intellectual disabilities permanent sterilization such as tubal ligation or ablation of the endometrial lining which may be far safer than the long acting hormone treatments that are currently being given for either birth control or for improved personal hygiene. Because of the spectre of past abuses related to involuntary sterilizations, there is an assumption that sterilization would never be in the best interests of a woman with an intellectual disability. Although it was stated that the principle of *parens patriae* should not be used by the courts to give consent for non therapeutic sterilization, the emphasis in this ruling was that it should not be used for the benefit of Eve's mother.

The court's function to protect those unable to take care of themselves must not be transformed so as to create a duty obliging the Court, at the behest of a third party, to make a choice between two alleged constitutional rights--that to procreate and that not to

procreate--simply because the individual is unable to make that choice. There was no evidence to indicate that failure to perform the operation would have any detrimental effect on Eve's physical or mental health. Further, since the *parens patriae* jurisdiction is confined to doing what is for the benefit and protection of the disabled person; it cannot be used for Mrs. E.'s benefit. (E. (Mrs.) v. Eve (1986). pg 4)

A similar case may have gone differently if an independent representative had argued that recurrent menstrual cycles were restricting the physical freedom of a particular woman with an intellectual disability. Given the risks of lifetime hormonal manipulation that might be detrimental to the physical health of the woman, it may very well be in her best interests to have a hysterectomy or endometrial ablation as a means of eliminating the menses. Physicians and lawyers alike have backed away from the issue, and women with intellectual disabilities continue to receive hormonal therapies unnecessarily. Doctors obtain consent from substitute decision makers to give long acting birth control injections to women with intellectual disabilities from menarche to menopause. Twenty years after the Eve case, we have more information about the risks of hormone therapies: if we were to reopen the debate, would the Supreme Court rule differently if there was a more thorough debate of "the best interests" of the woman with an intellectual disability?

Giving consent for transplantation is also mentioned specifically in the *Health Care Consent Act* and the *Substitute Decisions Act*, and the Guardian must follow the laws regarding transplantation. Live donors must give informed consent. Organ donation is considered an altruistic act which does not benefit the donor. For that reason it could be assumed that it is never in the best interests of a person who is incompetent to be a live donor for transplantation. There is an interesting case from the United Kingdom which highlights the need to make an assessment on an individual basis. There may be situations where it would be appropriate for a substitute decision maker or the courts to decide to allow for a live donation of an organ from a person who has an intellectual disability.

Re Y [1996] 35 BMLR 111 Patient (Y) was 25 years old, severely mentally and physically handicapped. She lived in a nursing home but had a close relationship with her family. One of her three sisters suffered from leukemia and needed a bone marrow transplant. The patient was the only suitable donor. The court considered that it was in Y's best interests to donate bone marrow to her sister even though there was no therapeutic medical benefit to Y (and a minimal risk to Y from the procedure). The court considered that it was in Y's emotional, social and psychological interests, since, if Y's sister died; Y's mother would have to look after the sister's daughter, and therefore, be unable to spend as much time visiting Y in the nursing home. (UK Clinical Ethics Network)⁶

It would be important to ensure that there is a mechanism within the *Substitute Decisions Act* to allow substitute decision makers and the Public Guardian to access the courts or an external review panel if there is uncertainty about what are the "best interests" of a particular individual. If policies are created as generalizations of the judgments on specific cases before the court, there is a risk that individuals may not have their own best interests considered. It might be considered discriminatory if policies were made in order to deny certain procedures purely because a person was a member of a group with a permanent disability. There ought to be a legal mechanism to determine what is in the best interests of any particular individual with an ID. Perhaps the Consent and Capacity Review Board could be a venue for these discussions.

⁶ UK Clinical Ethics Network, <http://www.ethics-network.org.uk/Ethics/econsent.htm>
(Accessed July 1, 2006)

Consent and Capacity Review Board

The Consent and Capacity Review Board is an independent body created by the provincial government of Ontario. It conducts hearings under the *Mental Health Act*, the *Health Care Consent Act*, the *Personal Health Information Protection Act*, and the *Substitute Decisions Act*. Board members are psychiatrists, lawyers and members of the general public appointed by the Lieutenant Governor in Council. The Board sits with one, three, or five members. Hearings are usually recorded in case a transcript is required.⁷ A person with a psychiatric disability who has been deemed incompetent or is detained in a psychiatric facility is visited by a Rights Advisor and is informed of his right to request a hearing before the Consent and Capacity Review Board. If he indicates a desire to request a hearing, he is represented at the hearing by a Legal Aid lawyer. This process is not available within the agencies guided by the *Developmental Services Act*.

For historical reasons, persons with intellectual disabilities (ID) have been treated differently. In 1974, developmental services moved from the Ministry of Health to the Ministry of Community and Social Services. Since 1974, the legal rights of persons with psychiatric disabilities have improved dramatically with several iterations of the mental health legislation; *however*, little has changed for persons with ID. The Ministries of Community and Social Services (MCSS) and Health and Long-term Care (MOHLTC) have for many years recognized the overlap in responsibilities for persons with ID who also have mental health needs (dual diagnosis). (MCSS, 1997) The prevalence rate for dual diagnosis is conservatively estimated to be 38% of persons with ID. (Yu, 1993) It would appear to be discriminatory that persons with intellectual disabilities and a mental health concern do not receive advice concerning their rights and do not have access to legal counsel.

Under the *Mental Health Act* 39(4), on the completion of a fourth certificate of renewal and on the completion of every fourth certificate of renewal thereafter, the patient shall be deemed to have applied in the approved form under subsection (1) to the Board unless he or she had already applied under clause (2). This means that the case of every patient held under the *Mental Health Act* is reviewed by a Consent and Capacity Review Board every twelve months whether they are competent or not. In this review process they are represented by legal counsel. Similarly, persons who are deemed not fit to stand trial or who are in a forensic psychiatric institution because they have been found not criminally responsible have annual hearings before the Ontario Review Board which has been established by the Criminal Code of Canada.⁸ This annual review process which is available under both the Criminal Code of Canada and *the Mental Health Act*, 1996 **is not available** for persons living in facilities and institutions under the *Developmental Services Act*.

The **case of L. (2006)**⁹ highlights the necessity for this mandatory review.

Ms. L. was a patient at [this] facility. The Board convened in accordance with the statutory requirements of section 39(4) of the *Mental Health Act* for a mandatory review of her

⁷ Information obtained from www.ccboard.on.ca (accessed July 2, 2006)

⁸ <http://www.orb.on.ca> Ontario Review Board Website (Accessed July 2, 2006)

⁹ <http://www.canlii.org/on/cas/onccb/2006/2006onccb10004.html> (Accessed, July 2, 2006) Reasons for decisions of the Consent and Capacity Review can be accessed through the Consent and Capacity Review Board Website. <http://www.ccboard.on.ca>

involuntary status. The risk set forth in the Certificate of Renewal (eighth) dated January 18th, 2006 as assessed by the attending physician was “serious physical impairment of the patient” pursuant to section 20 (5)

Ms. L., a 55 year-old lady with a mild level of intellectual disability, was a patient at an Ontario psychiatric hospital and was considered an elopement risk which put her at danger from both the elements as well as from strangers. She was generally sociable and did not have any psychotic symptoms. Her attending psychiatrist acknowledged that Ms. L. would not be in the psychiatric facility if other support and accommodations were available in the community. Ms. L. stated that she wanted to live in another residence and felt it was unfair to have lived so long in this facility with its restrictions.

The analysis of the Review Board concluded that Ms. L.’s mental retardation combined with at least two elements of difficulties with adaptive functioning constituted a mental disorder. The panel agreed the wandering in all weather, the past elopements and the problem with dietary and medication compliance were sufficient to establish the risk of serious physical impairment to Ms. L., and therefore, she was not suitable to remain as a voluntary patient. The main point of disagreement among the members of the Board was whether the psychiatric facility was the best place for Ms. L. to reside. The attending psychiatrist acknowledged Ms. L. had no real privileges on or off the ward, was confined in a secure area, was subject to seclusion from time to time due to agitation and was not able to come and go as she pleased. The Lawyer Member of the Review Board had a dissenting opinion from the Psychiatrist Member and the Community Member, and it is recorded.

Was this what the legislature intended when it included the phrase “unless the patient remains in the custody of a psychiatric facility”? With respect, the Lawyer Member answered this question in the negative.

The phrase meant an individual suffered from mental disorder, required treatment, was not suitable to be voluntary and needed to be in a psychiatric facility to achieve those ends. In the community Ms. L. would live in a less restrictive environment with some personal dignity.

Though it was clear all healthcare providers cared very much for Ms. L. and had her best interests at heart, compelling her to remain in a psychiatric facility was an abuse of her freedom and dignity.

If society has not provided adequate alternative accommodation and supports, did that justify the virtual incarceration (or at least, detention) of an individual because there was no place else for her to go? To say it was in her “best interests” to remain at this facility was to go contrary to the case law and the spirit of the legislation. It was paternalistic and, with respect, not acceptable. (Dissenting opinion, Lawyer Member, L. Re, 2006, ON CCB)

The majority of the Board confirmed the involuntary status of Ms. L. despite all agreeing with the attending psychiatrist that Ms. L. would not be in a psychiatric facility if other supports and accommodations were available.

Although Ms. L. would remain in a psychiatric facility, the case had been reviewed by an independent Board and the situation would be reassessed on an annual basis as long as she remains an involuntary patient. The Lawyer Member found it unacceptable to use a psychiatric facility as a “holding pen” until “something else” comes along. His dissenting opinion is public. For reasons of confidentiality, clinicians who are aware of such cases are unable to speak out. Without an independent and regular review of such cases, it is difficult to ensure that Ontario citizens with ID are living in the least restrictive environment possible. It is also difficult to assess the number of similar cases of patients with ID who perhaps are not certified because they are compliant to the rules of the institution.

This case brings forward several interesting issues: First, there is debate that an intellectual disability should be considered a mental disorder as it pertains to the *Mental Health Act*. Disability activists would not want persons with an ID to fall under the *Mental Health Act* on the basis solely of the intellectual disability. On the other hand, the *Mental Health Act* does provide more legal protection and independent oversight for persons in psychiatric facilities than the *Developmental Services Act* does for persons in the three remaining institutions managed by the MCSS. A good percentage of persons in those institutions have a psychiatric condition or behavioural disorder which would meet the criteria for the *Mental Health Act* if they were in a psychiatric facility. This would appear to be discriminatory on the basis of their disability, and it would appear that their detention in a facility under the *Developmental Services Act* is arbitrary. Someone with more legal expertise than the author would need to decide whether there were grounds to initiate a Charter challenge.

Class Action – Rideau Regional Centre

Ironically, the class action suit (*Gray v. Ontario*)¹⁰ that arose regarding the residents of Rideau Regional Centre (RRC) was not a Charter challenge but rather an attempt by relatives of the residents to keep the institution open and to stop their relatives from moving into community settings. In September of 2003 the MCSS announced its intention of closing down the last three remaining government institutions for persons with developmental disabilities by March 2009. This caused much consternation among relatives and resulted in a class action suit which was heard before the Ontario Superior Court of Justice. The two issues in question were:

- (1) Did the Minister exceed her jurisdiction under the *Developmental Services Act* by directing the closure of the remaining schedule 1 facilities (the RRC, HRC and SRC)?¹¹
- (2) If the Minister acted within her jurisdiction in closing the institutions, is the Minister required to obtain the consent of the resident or his or her next of kin or substitute decision maker for the community placement selected for the resident? If so, how are disputes to be resolved concerning community placement?

The answer to the first question was affirmative in that the *Developmental Services Act* states that the Minister ‘may’ operate facilities, and thus, the Minister was permitted to close the facilities. On the second issue, Justice Hackland stated that he was ‘of the opinion that the consent of a developmentally disabled adult or his or her substitute decision maker is required for any choice of community residential placement. This is because of the direct and substantial effect this choice will have on the individual’s health, safety and personal welfare, and it is in accordance with the principles of fundamental justice. It is well within the jurisdiction of the Superior Court of Justice, in the exercise of *parens patriae* jurisdiction, to declare this right and

¹⁰ *Gray v. Ontario* 2006 CanLII 1764 (ON.S.C.D.C) January 26, 2006.

<http://www.canlii.org/on/cas/onscdc/2006/2006onscdc10007.html>

¹¹ Rideau Regional Centre, Huronia Regional Centre and Southwestern Regional Centre

to see that it is respected.”(Gray, [33]) Further he states that “the issues likely to arise in implementing the community placements may, in whole or in part, be covered by the provisions of the *Health Care Consent Act*, 1996 or the *Substitute Decisions Act*, 1992. To the extent they are not, this Court will exercise its inherent *parens patriae* jurisdiction for the protection of the welfare of these mentally incapable adults.” (Gray, [41])

Justice Hackland then points out the limits of the two afore mentioned acts. The *Health Care Consent Act*, 1996 does not apply to admission to a group home as it is not a “care facility” as defined in section 2(1) of the Act. The *Substitute Decisions Act*, 1992 also does not directly address the issue of consent in relation to the admission of an incapable person to a group home or other community setting. The judgment wrestles with the complexities of each of the laws and their intent. Despite being unable to dictate a process for obtaining consent to community placements that will apply in every case, the object will always be the same, which is to act in the best interests of the incapable person. (Gray, [47]) The Ministry has the authority to close the institutions but must obtain consent for community placements. The families are encouraged to cooperate with the process and any disagreement between the substitute decision maker and the Ministry of Community and Social Services may be resolved by application to the Superior Court of Justice. (Gray, [53(c)])

It is because there is a gap in the existing legislation that the *parens patriae* jurisdiction comes into play. This class action lawsuit has highlighted the legal gap for these 1000 residents who will be moving into community placements over the next few years. The gap in legislation will remain when they are in the community, and the gap exists for the many thousands more who are already living in accommodation regulated by the *Developmental Services Act*, 1990.

Conclusions

This paper has examined the legislation relating to consent and substitute decision making and explored the implications of this legislation for persons with ID. There are several areas where persons with ID are treated differently than persons who have been competent in the past and may be competent in the future. Because of a decision in 1974 to place the management of developmental services under the Ministry of Community and Social Services, persons with ID have not benefited from the significant improvements in legislation which applies to Ministry of Health and Long Term Care facilities over the past thirty and some years.

Advocacy efforts should focus on systemic issues, such as the low level of funding for community supports and the unintentional discriminatory policies of a government and current legislation which treat persons with ID differently from persons with other disabilities. There should be discussion about the creation of a mandated independent review process for care plans for persons with moderate to severe intellectual disabilities. According to the *Substitutes Decision Act*, the Public Guardian has the power to investigate situations of potential abuse or neglect of adults. However, a Provincial Office for Vulnerable Adults may be a better way to address the breadth of potential abuse and neglect that persons with ID, the elderly and those with acquired brain injury may experience.

With the closing of the last three institutions, the Government of Ontario is getting out of the business of providing direct service to persons with ID. However, it will still be accountable for the quality of the services funded through transfer payment agencies. It would be helpful to look at the gaps in legislation identified by Justice Hackland (Gray vs Ontario, 2006) and consider how they may apply to group homes. Clarity is required on the role of the substitute decision maker/court appointed Guardian so that someone is legally capable of giving consent for

personal care issues as well as behaviour support plans and medications. There should also be a clearer and more routine mechanism to examine a situation when it is thought that the substitute decision maker is not acting in the best interest of the incompetent person.

The establishment of an Advocacy Office for Adults receiving services under the Developmental Services Act, similar to Child and Family Service Advocacy, should be considered as a mechanism to improve advocacy. As well it would be a resource for professionals and families who often have difficulty understanding the intricacies of the laws pertaining to persons with intellectual disabilities who may be incompetent.

It is important to reexamine policies that have been based on individual cases and then generalized to a whole class of persons. This is potentially discriminatory if someone is denied a procedure simply because they are a member of a larger group, such as persons with ID. Ideally, there should be an easily accessible and clear process which can make decisions for a particular individual as to whether a procedure is in the individual's best interest or not. Alternate forms of decision making should be considered so that a person may be as involved in the decision making process as he/she is capable.

The MCSS is committed to individualized planning for persons with intellectual disabilities so that they can be included in society and live full meaningful lives. These are good goals and legal safeguards must be adequate to ensure that this is possible in a fair and safe manner for all concerned. Society has had a tendency to exclude and mistreat persons with ID (Foucault, 2003). In order that we do not see a repetition of the past, there must be a mechanism to identify potential abuse as well as adequate resources for providing support and ongoing monitoring of services and programs for persons with ID. The least restrictive environment should be encouraged -- but not if it is only possible with excessive medication or physical restraint or seclusion. Independent reviews should be encouraged as routine and seen as learning experiences. There needs to be more transparency in the system without sacrificing confidentiality.

Legislation should protect the vulnerable adult and should also facilitate the care and support of persons with ID who are not competent to make the big decisions in their lives. It should provide them with the freedom to make the choices that would enhance their quality of life. Those who care for and support persons with ID should consider the best interest of each unique person at all times.

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NEW RESOURCE AVAILABLE

The 2008, 38:204-206 issue of the *Journal of Autism and Developmental Disorders* included a review of a new book entitled ***Diagnostic Manual - Intellectual Disabilities: A Textbook of Diagnoses of Mental Disorders in Person with Intellectual Disabilities (DM-ID)***. One of the editors includes Dr. Chrissoula Stavrakiki, from Ottawa and long time expert practitioner in the field of intellectual disability and psychiatric disorders. The textbook is printed by the NADD Press, NY, 360 pp., ISBN-13: 9781572561250. \$96.00 (paper).

A shorter volume, **Diagnostic Manual-- Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability** has been abridged for clinical usefulness. It focuses on issues related to diagnosis in people with ID, the limitations in applying DSM-IV-TR criteria to people with ID, and adaptation of the diagnostic criteria.

Ordering info available thru <http://www.dmid.org/>
or <http://www.thenadd.org/>

Copies of the articles below are available from Derrick MacFabe via email at dmacfabe@uwo.ca and the following article - "**Neurobiological effects of intraventricular propionic acid in rats: Possible role of short chain fatty acids on the pathogenesis and characteristics of autism spectrum disorders**" – by MacFabe, Derrick F. et al., is on his website:
<http://www.ssc.uwo.ca/psychology/pdfs/autism/MacFabe%20etal07.pdf>

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A Novel Rodent Model of Autism: Intraventricular Infusions of Propionic Acid Increase Locomotor Activity and Induce Neuroinflammation and Oxidative Stress in Discrete Regions of Adult Rat Brain

Derrick F. MacFabe, Karina Rodríguez-Capote, Jennifer E. Hoffman, Andrew E. Franklin, Yalda Mohammad-Asef, A. Roy Taylor, Francis Boon, Donald P. Cain, Martin Kavaliers, Fred Possmayer and Klaus-Peter Ossenkopp
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Intracerebroventricular injection of propionic acid, an enteric bacterial metabolic end-product, impairs social behavior in the rat: Implications for an animal model of autism

Sandy R. Shultz^{a,*}, Derrick F. MacFabe^b, Klaus-Peter Ossenkopp^a, Shannon Scratch^c, Jennifer Whelan^c, Roy Taylor^c, Donald P. Cain^a

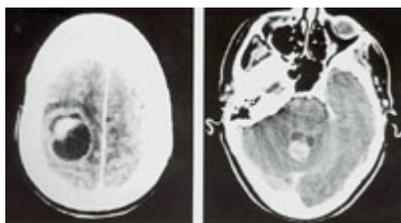
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AN E-LEARNING MODULE

Epilepsy in intellectual disability

by Professor Shoumitro Deb and Dr Radha Srikanth



In the general population, the risk of an individual developing epilepsy in his or her lifetime is between 3% and 5%.

Approximately 14%-24% of patients who have intellectual disability have epilepsy.

Epilepsy in persons with intellectual disability means more than having epileptic seizures as it also involves the issues of quality of life, carer involvement and attitudes, managing medications with associated adverse reactions and risk management with an aim to establishing a better quality of life for the person and her/ his family carers.

This module aims to provide you with an understanding of the relationship between epilepsy and intellectual disability as well as how to assess and manage epilepsy in patients with intellectual disability.

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