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Consent to care of persons with intellectual disability in Quebec: from vulnerability to capability

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Abstract

Persons with an intellectual disability (ID) who interact with the Quebec health and social services system are faced with major decisions regarding the care they are offered. As consent to care derives from the fundamental right of all persons to personal inviolability and to autonomous decision making, they therefore have the right to accept or refuse any and all health and psychosocial care proposed. However, as free and informed consent to care must be given by an able person, the situation becomes somewhat more complicated whereas persons with ID are concerned. This article presents reflections on the challenges and issues relative to these persons' consent to health and psychosocial care.

Keywords: intellectual disability; ethics; consent; patientcentered care; human rights Caux C, Lecomte J.
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Resumen

Las personas con discapacidad intelectual (ID) que interactúan con el sistema de salud y los servicios sociales de Quebec se enfrentan a decisiones importantes sobre la atención que se les brinda. Dado que el consentimiento a la atención se deriva del derecho fundamental de todas las personas a la integridad personal y a la toma de decisiones autónomas, éstas tienen el derecho de aceptar o rechazar cualquier atención de salud y psicosocial que se les proponga. Sin embargo, como el consentimiento libre e informado a la atención debe ser dado por una persona apta, la situación se vuelve más complicada en las personas con ID. Este artículo presenta reflexiones sobre los desafíos y temas relativos al consentimiento de estas personas hacia la salud y la atención psicosocial.

Palabras clave: discapacidad intelectual; ética; consentimiento; atención dirigida al pariente; derechos humanos

The prevalence of intellectual disability (ID) in the general population has long been estimated at 1 to 3%. About 88% of persons with ID are considered mildly disabled. ID is not a mental disorder; it is a condition. In Quebec, Canada, the deinstitutionalization of

the past 20 years and the development of policies such as Social Integration to Social Participation⁴ reflect a major shift in the status assigned to people with ID in society. As it drifts away from the biomedical institutionalization model, society today recognizes that persons with

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ID have the same fundamental rights as others.⁵ In this regard, the vast majority of persons with mild ID in Quebec do not live in an institution but rather in the community. Like any other citizen, they have access to education and employment and can have a social and/or romantic life. Community integration is supported, in particular, by a network of rehabilitation centers for persons with ID. These offer a broad array of habilitation, rehabilitation, residential and community integration services, including physical health care, sexual health education, school support, employment support, and home-living support.⁶

The Civil Code of Québec stipulates that "every person is inviolable and is entitled to the integrity of his person". Hence, "no one may interfere with his person without his free and informed consent". The Civil Code of Québec makes this principle explicit by tying it unequivocally to the notion of care. Thus, "care" without free and informed consent constitutes a violation of a person's integrity. This notion of "care" covers examinations, tests, taking of samples or specimens, treatments, immobilization, hospitalization and isolation, be it for medical, psychological or social reasons, whether or not required by a person's physical or mental state of health.

In fact, based on this holistic definition of "care" adopted in Quebec law, all health and psychosocial services offered to persons with ID constitute "care". It follows, then, that this care, being as it is intimately tied to the notions of personal inviolability, autonomy and will, is unequivocally subject to their consent.^{7,8,10} This requirement was echoed in recent statements by the Special Rapporteur of the Commission on Human Rights on torture and other cruel, inhuman or degrading treatment or punishment, who reiterated that healthcare delivered non-consensually was tantamount to torture as defined under international law. 11 Moreover, as recognition of the right of all persons to self-determination and autonomous decision-making is the cornerstone of social integration, ¹²⁻¹⁴ there is no sidestepping the issue of consent to care in the context of ID services offered by Quebec's health and social services system.

Recognizing the necessity of consent to care from persons with ID marks a radical break with the historical biomedical model of intervention. Under this model, all decisions regarding care delivered to persons with ID, including those with only mild ID, were made by a substitute decision-maker, be it a parent, a physician or a social worker¹ without taking account of the person's fitness to give or refuse consent to care. This systemic assumption that all persons with ID, including those with only mild ID, are permanently incapable of making decisions regarding all aspects of their life is, ap-

parently, a worldwide phenomenon.¹ This assumption increases the risk of their fundamental rights not being respected and thus curbing their social integration and participation.^{1,15,16} However, obtaining consent to care from these persons entails a number of challenges and issues in actual practice. We will dwell, in particular, on those inherent in the evaluation of capacity to consent. In addition, because these persons could, like any other citizen, need support to make decisions regarding their care, we will examine the idea of supported decision-making where those requiring it are more vulnerable than others.

Evaluating capacity to consent to care

Unlike fitness to stand trial or to manage one's belongings, capacity to consent to care is a concept that must be adapted to each different context of intervention. Indeed, even though persons with ID may be deemed incapable in some spheres of their civilian life, they can nevertheless be perfectly capable to consent or not to psychosocial interventions, such as moving to a new residential resource or support offered to take on a new job. Regarding the interrelation between capacity, its evaluation and context of intervention, certain authors have pointed out that service providers tend to consider persons capable as long as they accept the care they are offered. Their capacity is questioned only when these same persons express an unwillingness or refusal to accept care which is unreasonable to the eyes of the service providers.^{17,18} This view of capacity is pernicious for two reasons. First, accepting that persons clinically incapable to consent to care nevertheless make decisions concerning their care constitutes a violation of the fundamental right of these vulnerable persons to being protected. Second, equating any refusal to accept care by persons otherwise capable to consent to care with being incapable to make decisions for themselves can carry heavy consequences for these persons. This confusion can in fact trigger a "domino effect" leading potentially to a violation of their fundamental rights via, for example, negation of their right to choose where to live, restriction of their freedom to go as they please, or limitations on their freedom to frequent whomever they choose.¹⁹

Capacity thus becomes a multi-nuanced concept that depends on the care proposed and requires a refined and contextualized evaluation. Quebec law attributes to physicians, and particularly psychiatrists, a predominant role in the evaluation of a person's capacity to consent to care. ²⁰ However, as such professionals are essentially absent from the network of rehabilitation centers for people with ID, this evaluation becomes difficult to implement,

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in concrete terms, in the context of the delivery of daily services, which are part of the holistic definition of "care" adopted in Quebec law. Consequently, the role of evaluator befalls clinicians; they are the ones, with the support of multidisciplinary teams, to decide whether a person is capable of giving consent.

In the absence of evaluation tools or of measures of clinical capacity to consent to psychosocial care, Quebec clinicians who work with persons with ID have adopted methods and practices used elsewhere in Canada. ^{21,22} In particular, they apply the so-called Nova Scotia criteria, ^{23,24} which were initially tied to the specific context of court-ordered mental health treatment. Under these criteria, a person is deemed capable of consenting to care if:

- 1. They understand their illness or condition.
- 2. They understand the nature and aim of treatment.
- They understand the potential risks of undertaking treatment.
- They understand the potential risks of foregoing treatment.
- 5. Their condition does not generally impair their faculties and judgement.

Though these criteria have been recognized by the Supreme Court of Canada, as well as the Quebec Court of Appeals, for evaluating capacity to consent to care, there are reasons to believe that there application renders them ill-suited to care, including that of a psychosocial nature, offered to persons with ID.

First, strictly speaking, psychosocial care does not constitute curative treatment. In fact, what service providers propose are adaptation or rehabilitation measures. These are not defined as a function of the user's illness but rather on the basis of a condition, that is, their ID. Second, notwithstanding the use of the term "treatment", these criteria refer to the inherent benefits and drawbacks of care offered to persons with ID. Informed consent, then, entails engaging in a nuanced conceptual analysis of the probability of future events rather than merely assessing existing facts. As it happens, such an exercise of conceptualization or abstraction can be arduous for persons with ID.²⁵ Indeed, they may not always be able to fully grasp the concepts of risks and benefits related to the delivery of care²⁶ and to weigh its pros and cons.^{27,28} Research results suggest, also, that persons with ID feel they get short shrift from professionals, have difficulty understanding what they say,29 and do not possess a proper appreciation of their right to accept or refuse care. 30 Finally, driven often by social desirability and the fear of being evaluated, judged and reprimanded, persons with ID tend also to accept whatever is proposed,

especially if offered by a person of authority, and are inclined to choose the last option presented.³¹

There is reason, then, to exercise caution when transposing the above criteria to the context of interventions for persons with ID lest these criteria be applied perfunctorily or improperly. Caution is especially important regarding the 5th Nova Scotia criterion to the effect that a person's condition should not generally impair their faculties or judgement. Though persons with ID could actually be incapable to give consent, in which case substituted consent is required, this last criterion seems the most problematic of all those advocated by Canadian jurisprudence for evaluating fitness to consent to care. The problem with this criterion lies in its lack of nuance regarding ID. There is no denying that ID is a condition whereby a person's faculties and judgement are generally affected.³² Whereas this criterion is clinically significant in the context of mental illness where a person's ignorance or non-recognition of their disease is very often the key factor in its maintenance,³³ it is not necessarily so in the context of ID. This criterion could thus potentially pervert the clinical evaluation of fitness as it leaves the door open to the assumption that persons with ID, including those with only mild ID, are intrinsically incapable to give consent.

Further, these criteria derived from jurisprudence lead to a dichotomous judgment (yes/no) regarding capacity to consent.³⁴ However, reality is often much more complex. Indeed, the fitness of people with ID to consent to care, especially in the case of psychosocial care, can vary according to the person offering the care, the person offering it, or even to the time of day the care is offered.³⁵ What's more, people with ID may be unfit to consent to care by themselves but perfectly fit to do so with the support of a significant friend or family member.

One way of possibly remedying the difficulties inherent in the evaluation of fitness and the consent to care of persons with ID, then, is to give them the assistance they need to make decisions for themselves. Such support, however, raises a number of questions.

Supported decision-making

The need for such support finds justification particularly in the concepts of risk and vulnerability. Indeed, populations with ID can be qualified as vulnerable on account of shared characteristics that potentially expose them to various risk factors.³⁶ This vulnerability is tied, in particular, to notions of frailty, precariousness, proneness to being exploited, and injustice.³⁷ Clearly, without this vulnerability or potential exposure to risk factors there would be no reason to "support" these persons

make decisions for themselves. However, this risk or vulnerability remains the product of an inter-subjective interpretation process between the parties involved in decision-making in a given context.³⁸ This process can become a source of tension between the person with ID and the persons helping them make decisions. In supported decision-making, a risk comparison and negotiation process is set into gear to determine acceptable risk. This acceptable risk does not exist outside of the representation that the parties involved make of it given the inherently tautological nature of risk acceptability. After all, risk is acceptable if it is accepted.³⁹ As it turns out, any help provided in support of decision making is heavily tainted by the meaning ascribed to acceptable risk, especially if the person with ID is perceived by those flanking them in the decision-making process as (very) vulnerable. The inherent complexity of providing such assistance is perhaps why there is no single model of supported decision-making. 40 Indeed, although such support holds the promise of empowering persons with a disability and respecting their dignity, there is very little empirical evidence backing this concept. 40 In this regard, Kohn noted that the number of publications on how supported decision-making should work was growing but that very few scientific studies examined how this concept was actually put into practice.⁴⁰ Similarly, there is a paucity of data on the relationship between support provider and decision maker. Does this relationship contribute to render the person with ID more autonomous or, on the contrary, does it increase their sense of dependence and vulnerability to manipulation, not to mention the risk of abuse?⁴⁰

A grassroots initiative

Various options have recently been explored to take account of the numerous limitations inherent in the evaluation of fitness, supported decision-making, and consent. Among these, a clinical-legal intervention committee (CLIC) was established in 2012 at the largest rehabilitation center for people with ID in Quebec. The committee arose from the convergence of three factors: a review of the literature on the interface between the law and clinical practice, 41 a decorated pilot project (Leading Practice of Accreditation Canada, 2007), and a grant from the Canadian Foundation for Healthcare Improvement. The purpose of the CLIC was to guide and support clinical teams and managers with respect to service users exposed to high risks for themselves, others or the establishment. The term clinical-legal refers to the committee's sphere of intervention, which covers matters of a clinical, legal or administrative

nature, as well as its composition of clinicians, administrators and lawyer.

The CLIC serves as a forum and arbitrator for various considerations, including clinical, legal, ethical, and resource-allocation issues, relative to interventions in connection with the establishment's mission. Normally, this committee is called upon to examine situations where the perception and assessment of risk, capacity, consent and refusal constitute a major issue for persons with ID, their social support network, and the establishment.

Because the CLIC focuses its attention on problems that stand at an apparent impasse, it contributes also to foster the professional development of the different players part of the user's care continuum. The CLIC aims to improve the cohesion among the legal, clinical and organizational dimensions inherent in various situations over the course of intervention. It seeks to do so through education and the development of certain "reflexes" among the players concerned. Indeed, a better understanding of the concepts at the root of daily challenges and issues makes it possible to better specify practices and greater specification can only be beneficial for the social integration and participation of persons with ID.

Conclusion

The issues and concepts relative to obtaining consent to care from persons with ID remain vast and numerous. Given the legal, social and economic impact of the multiple dimensions of the consent process, there is reason to wonder how these dimensions are articulated in real situations of clinical practice. In this regard, based on a critical review of some 30 publications, Goldsmith and colleagues¹⁹ concluded that research must be conducted on the consent of persons with ID in order to remedy the lack of knowledge on the subject and to foster recognition of the fundamental rights of these persons. In many parts of the world, persons with ID are discriminated against in terms of their right to make decisions for themselves regarding their health, wellness and living environment.¹ This lack of control over such decisions is not without consequence for their health. Indeed, according to various authors, 42-45 respect of a person's fundamental rights has a positive effect on their state of health and, inversely, the violation of these rights has a negative impact on it. This link between state of health and the law is exacerbated in populations with IDowing to their vulnerability. Supported decision-making, recognition of their decision-making autonomy, and this population's consent must thus be intimately related to the respect of fundamental rights.

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