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Promoting decision-making capabilities in health care of adults with intellectual and developmental disabilities: Ethics and practice

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Abstract

Supported decision making approaches in health care recognize the authority of persons with intellectual and disabilities to decide on certain treatment options with the help of close and trusted persons as needed. This paper (a) elaborates on supported decision making in health care, (b) discusses some possible philosophical and ethical underpinnings of this approach, (c) concludes that a supported decision-making approach affirms the inherent dignity of persons with intellectual and developmental disabilities and can enable them to make and authorize healthcare decisions in ways that are recognized, and (d) will give examples of and helpful tools for implementing supported decision making in healthcare practices. Further inquiry is needed, however, regarding specific barriers to and facilitators of these practices.

Key Words: Intellectual Disability; Capabilities Approach; Supported Decision Making; Shared Decision Making; Relational Autonomy

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Introduction

Adults with intellectual and developmental disabilities are likely to be found on the margins of healthcare systems. They experience high rates of poverty, exploitation, and trauma (Brucker & Nord, 2016; Hughes et al., 2012; Byrne, 2019). Many are socially isolated (Hurd et al., 2018).¹ Their health needs, which often are multiple and complex, can go unrecognized and unaddressed (Williamson et al., 2017; Hughes-McCormack et al., 2018; Sullivan et al., 2018).²

These challenges are compounded by experiences that such adults have of being on the periphery of decision making regarding their own health care (Hoole & Morgan, 2011). Potvin et al. (2019) found that support to navigate health systems and person-centred care (e.g., respect for decision-making capabilities, communication, rapport, and advocacy) were what adults with intellectual and developmental disabilities said they needed to better access primary care assessments. When deemed to lack capacity to make healthcare decisions on their own, adults with intellectual and developmental disabilities usually have these decisions made for them by healthcare providers and caregivers, often informally, and by legally recognized substitute decision makers or surrogates.

Recently, supported decision making has been proposed as an approach to healthcare decision making that challenges fundamental premises of contemporary western bioethics and health law, as well as prevalent healthcare practices. Supported decision making is sometimes confused with shared decision making, which is a well-established aspect of person-centred health care. The

main difference between these two approaches is that, in shared decision making, the person needing health care is assessed to meet the criteria of legal capacity for healthcare decision making, whereas in supported decision making, the person requires the help of one or more supporters to meet those criteria.

This chapter (a) elaborates on supported decision making in health care, (b) discusses some possible philosophical and ethical underpinnings of this approach, (c) concludes that a supported decision-making approach affirms the inherent dignity of persons with intellectual and developmental disabilities and can enable them to make and authorize healthcare decisions in a way that is recognized, and (d) will give examples of and helpful tools for implementing supported decision making in healthcare practices. Further inquiry is needed, however, regarding specific barriers to and facilitators of these practices.

I. Supported decision making in health care

There is no universally accepted definition of supported decision making in healthcare publications (Davidson et al., 2015). The term is sometimes used, broadly, to refer to an aspect of person-centred approaches to health care, which aim to be *supportive* of persons when they make healthcare decisions. Understood in this way, supported decision making overlaps with what good clinicians are accustomed to do when they determine with persons their unique health needs and collaborate with persons and their caregivers in shared decision making concerning the person's goals of care and treatment options (Simmons & Gooding, 2017).

In disability law and policy, however, advocates mean by supported decision making something specific. It is an approach that recognizes the authority of persons to make decisions with the help of close persons whom they trust and who know them well (let us call them *decision-*

making supporters) (Bach & Karczner, 2010; Dinerstein, 2012). This understanding of supported decision making has only recently been applied in health care (Sullivan & Heng, 2018). Both shared decision making and supported decision making aim to enhance communication and promote collaboration between healthcare providers and persons needing health care to reach agreed-upon goals and plans of care; however, in shared decision making, consideration should also be given to how adults with intellectual and developmental disabilities might need to be accommodated and supported in order to participate in this process. The *Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Consensus Guidelines* state that “*Capacity for decision making is relational. Many patients with IDD can participate to some extent in decision making if provided with accommodations and supports by health professionals and family and other committed caregivers.*” (Sullivan et al., 2018, p. 259)

The significance of supported decision making is both ethical and legal. Recognizing someone’s capabilities and authority to make decisions is associated with respecting both their moral agency and status as a person equal to other persons before the law. Both of these are linked to respecting the social standing of persons with disabilities and their full inclusion and participation in society.

A major impetus to adopt supported decision making in law has been the United Nations’ *Convention on the Rights of Persons with Disabilities* (UNCRPD), hereafter abbreviated to *Convention*. 182 states are party to the UNCRPD as of December 2020, including Canada, which ratified the *Convention* on March 10, 2010. Article 12(1) obliges states party to the *Convention* to recognize the right of persons with disabilities “to enjoy legal capacity on an equal basis with others in all aspects of life” (United Nations, 2006, p. 10). Article 12(3) of the *Convention* stipulates that persons with disabilities should have “access to the support they may require in

exercising their legal capacity.” (United Nations, 2006, p. 10) According to the *Convention*, therefore, legal capacity is not only a right that persons with disabilities hold and should enjoy in common with other human beings. It is also a right that can be exercised and acted upon by all persons with disabilities, *regardless of the type or severity of their impairments*. The decisions that they arrive at, with supports as needed, should be legally recognized.

In its *General comment no. 1*, the United Nations Committee on the Rights of Persons with Disabilities states that, under the *UNCRPD*, “States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the *Convention*.” (United Nations Committee on the Rights of Persons with Disabilities, 2014, article 28, p. 6).

Several jurisdictions have changed or are beginning to change their legal frameworks to recognize supported decision-making approaches, e.g., Peru, Colombia, some states in the U.S., and some provinces in Canada. In these jurisdictions, supported decision making is being recognized as a complement or an alternative to guardianship and other substitute, surrogate or proxy decision-making arrangements in health care. Substitute decision-making arrangements, while well-entrenched in health law and health care in most countries of the world, take the authority for healthcare decisions away from persons who are deemed “incapable” or “incompetent” to make such decisions independently. In contrast, supported decision making would enable such persons to make healthcare decisions *inter-dependently*, i.e., with a range of accommodations, including those to address environmental sensitivities, stress or barriers to

communicating, training, and help from one or more decision-making supporters. Supporters can be trusted family members or others who know the person well enough to interpret the person's authentic values and to help affirm, select, and execute decisions regarding treatment options that best align with these values.

Decision making in health care is a process, the outcome of which is a decision to consent to or refuse treatments proposed by healthcare professionals. Some healthcare practices already involve persons as much as possible in the decision-making process regarding their health care. Nevertheless, as understood by the United Nations' *Convention*, supported decision making entails a radical re-thinking of who should authorize the treatment decisions of persons with intellectual and developmental disabilities. It questions prevalent practices such as assessing persons for decision-making capacity or competence without considering their need to be accommodated or supported, substitute decision makers or surrogates making decisions for persons who are deemed to lack capacity or competence when appropriate accommodations and supports are not offered to those persons, and involuntary medical treatments for such persons in their "best interests" when they are capable of refusing such treatments if provided accommodations and supports.

It is true that, in terms of outcomes, a person's supported decision could resemble a decision made on behalf of the person through a person-centred substitute decision-making process. For example, Daniel Sulmasy and Lois Snyder (2010, p. 1947) have proposed a "substituted interests" model of substitute decision making that "promotes the patient as a unique person, in the context of his or her relationships, applying the patient's authentic values, wishes, and real interests, as best they can be known." Section 4 of the *Mental Capacity Act* of the United Kingdom (2005) stipulates that decision makers on behalf of persons who are deemed to lack

capacity under the law should act on those persons' best interests. The *Mental Capacity Act* stipulates that, in so doing, substitute decision makers should "permit and encourage the person [i.e., the patient] to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him." Moreover, the substitute decision maker should ascertain, as far as is reasonable, "the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), the beliefs and values that would be likely to influence his decision if he had capacity, and the other factors that he would be likely to consider if he were able to do so. Legislation governing health care in several countries have similar provisions; however, most countries do not.

For advocates of supported decision making, there is a fundamental ethical and legal difference between supported and substitute decision-making approaches in health care. In supported decision making, the agency and legal authority of the person who is supported to make a healthcare decision is retained and recognized. In substitute decision-making approaches, that agency and legal authority for the decision ultimately rests with the substitute decision maker *acting on behalf of* the person. However much this substitute decision maker involves the person in the decision-making process, and however closely the decision matches what the person would have wanted based on the person's authentic values, it is the authority of *another person than the patient* that is being recognized as having ethical and legal weight and significance. Supported decision making practice cultivates the ethical, legal and social recognition of a person's agency in healthcare decision making, even if extensive decision-making supports are needed, including the interpretive support of family and friends. To the extent that substitute decision making, however well-intentioned, diminishes a person's legal recognition, it also diminishes these forms of recognition. Anderson and Honneth (2005) and Honneth (2007)

contend that substitute decision making constitutes systemic patterns of recognition that devalue a person's inherent dignity and equality in the eyes of those who must legally address the person as an object of another's care and decisions. They do not recognize such persons as subjects in their own right, however challenging and complex this may be.

It is important for healthcare providers, policy makers, and ethicists to attend to the perspectives of many persons with disabilities and their caregivers regarding this point. The claim is often made that designating persons with intellectual and developmental disabilities to be "incapable" or "incompetent" to make certain healthcare decisions in no way undermines respect for their personhood or inherent dignity. What many persons with disabilities and their advocates are saying, however, is that they experience substitute decision making differently. They can see how substitute decision making organizes the social *mis*-recognition of a person's agency.

Audrey Cole, who has a son with a severe intellectual disability, was an early advocate for legally recognizing supported decision making. Her persistent and pioneering work, together with that of her associates, lay the groundwork for article 12 of the United Nations' *Convention*. She writes: "Supported decision making is a formalization of the natural process that most of us use throughout our lives when making decisions: if we need help, we seek it. Few of us could say that we have never sought help or advice in making a decision. As long as our decision-making capacity is not questioned in the legal sense, we are free to seek and use whatever help we need in reaching decisions. No matter how critical the decision or how little, we truly understand its implications. If we have the capacity to seek support and are able to express our decision, there is no obligation to declare the support we had in reaching it. This is not so for people whose cognitive capacity is questioned, whether because of the inherent limitations of intellectual disability, as in my son's case, or because of diminishing cognitive capacity often brought on by

age. Unlike the rest of us, to maintain equality, those two groups are required to prove that they can make decisions independently. If they cannot, they are typically headed for the legal oblivion of incapacity and guardianship.... I believe that to be discriminatory.” (Cole, 2019).

Hence, increasingly, persons with disabilities and their caregivers are regarding legal capacity as fundamental to their being recognized as equal to others in society. They view societal structures or practices that are predicated on individuals having to demonstrate that they possess certain cognitive abilities in order to enjoy the legal recognition of decision-making capacity as manifesting an ableist bias that is often not adverted to or acknowledged. These set up norms and standards that discriminate against persons who lack such abilities and position them at a relative disadvantage to others in society. What philosophical and ethical arguments underpin supported decision making? These often are not as well articulated as legal ones. In the next section, we attempt a coherent philosophical and ethical framework for supported decision making.

II. Philosophical and ethical underpinnings

a. What is moral deliberating and deciding?

Bernard Lonergan (1972; 1988) has described human knowing as a composite of four distinct sets of cognitive operations that interact and are self-correcting: The first can be characterized broadly as *experiencing* data perceived by the senses or being aware of internal states and activities of consciousness; the second, as *understanding* or making sense of these data; the third, as *judging*, when we weigh the adequacy of evidence and check our understanding, and the fourth, as *deliberating and deciding*, when we aim to know what is good or worthwhile, and commit to act or refrain from acting in certain ways to attain it concretely (Lonergan, 1972;

1988, pp. 18-21). It is this fourth set of operations, which though related to and dependent on the others, constitutes us as *moral subjects* who encounter our world and act on it, for good or ill. In so doing, our decisions and actions shape the unique person that we each are and will become (Lonergan, 1996).³

Deliberating and deciding, like the other cognitive operations, are *intentional* operations. Elizabeth Anscombe (1958), in her influential work *Intention*, distinguishes non-voluntary actions (such as physiological responses and instincts) from voluntary decisions to act or refrain from acting in certain ways. These latter always have some purpose, aim or goal for the one who is deciding. It is something that this person either wishes to continue to enjoy or avoid in the present or hopes to realize or avoid in the future. The intention (or intentions) behind a decision, and not merely the outcome of this decision, has moral relevance.

Lonergan adds to this analysis by proposing that there is a fundamental, ultimate orientation behind all deliberating and deciding: All human beings, in virtue of being human, aim to enjoy and realize in their lives what is truly good, worthwhile or valuable. Lonergan calls this the transcendental intending of value. We could understand this in terms of a spontaneous desire to know what will bring about overall well-being for and among persons. Lonergan's view aligns with what diverse thinkers, among others, have described as striving to attain harmony, e.g., Confucius and Mencius; happiness understood as a flourishing human life, e.g., Aristotle, Aquinas; natural goods, e.g., Finnis (1980; 2011); the fulfillment of basic human needs, e.g., Abraham Maslow (1943); coherence with volitionally necessary commitments, e.g., Frankfurt (1999) or the cultivation of universally shared conceptions of human strengths, e.g., Dahlsgaard et al. (2005). Some examples of contributors to overall human well-being might be health, security, having positive connections with others, having a sense of belonging, engaging in

meaningful work or leisure, contributing to the common good, encountering beauty, and fulfilling spiritual longings.

Deliberating and deciding, for Lonergan, consists in judging whether certain concrete goals (e.g., enjoying this activity with this friend) align with my transcendental intending of value (does it truly bring about the overall well-being that I desire?) Alignment of the two is discovered or known when I experience an abiding complacency, a resting of one's heart, as it were. Lack of alignment can result in my becoming uneasy, agitated or concerned (Sullivan, 2005). We all become better over time at making good decisions through a self-correcting process, with the support of close and trusted persons on whom we rely for advice, guidance or modelling (e.g., parents, teachers, mentors, friends, members of one's cultural and religious communities).

Hence, deliberating and deciding are similar in structure to other cognitive operations, such as understanding and judging, because they are *intentional* (purposeful), and they can be *self-transcending* (i.e., our apprehending or discovering values can develop as we learn which goods in life genuinely bring about the overall well-being or fulfillment towards which all humans are oriented).

While deliberating and deciding are *cognitive* operations (they result in some discovery), they are distinct from other cognitive operations in that the pivotal insights on which they hinge, namely, *apprehensions or discoveries of value*, are "given in feelings." (Lonergan, 1972; 1998, p. 38)

The insight that a certain concrete good is worth pursuing or refraining from pursuing, as explained above, is felt. It is an affirmation that is accompanied by experiences of complacency or concern. This cannot be reduced to any strictly *logical* deduction. It is an instance of an affective rather than an intellectual cognition.

It is important to specify, however, that, drawing on the work of Dietrich von Hildebrand, Lonergan distinguishes moral feelings, which are intentional responses to what is genuinely good, worthwhile or valuable (i.e., responses to the transcendental notion of value, as explained above) from both non-intentional states or urges (e.g., fatigue, anxiety, hunger, thirst) and momentary or transient intentional responses to what is *merely* agreeable or disagreeable. Moral feelings can lead often to decisions to maintain or pursue what is agreeable or avoid what is disagreeable, but they can equally entail decisions to maintain or pursue what is disagreeable or arduous. Nonetheless, for Lonergan, moral feelings give “intentional consciousness its mass, momentum, drive, power. Without these feelings our knowing and deciding would be paper thin. Because of our feelings, our desires and our fears, our hope or despair, our joys and sorrows, our enthusiasm and indignation, our esteem and contempt, our trust and distrust, our love and hatred, our tenderness and wrath, our admiration, veneration, reverence, our dread, horror, terror, we are oriented massively and dynamically in a world mediated by meaning.” (Lonergan, 1972; 1988, p. 32) Moral feelings are thus *existentially significant* for each person. They are “so deep and strong, especially when deliberately reinforced, that they channel attention, shape one’s horizon, direct one’s life.” (Lonergan, 1972; 1988, p. 33)

In summary, deliberating and deciding entail apprehending or discovering values. Values can be authentic in both of these ways: (1) they are notions of what is good and worthwhile for enjoying overall well-being, which is what all humans intend or strive for, and (2) they are what truly matter to a person. They form the core of a person’s identity and are the source of goals or of what a person hopes for in life.

b. Can persons with intellectual and developmental disabilities hold and express authentic values?

From the above, it can be concluded that persons with intellectual and developmental disabilities or progressive neuro-cognitive impairments can hold authentic values. Like all other human beings, they are oriented toward what is genuinely for them good, worthwhile, valuable, and contributes or will contribute to their overall well-being. Through moral feelings, they are able to discover among concrete goods what aligns with this intention and, with support as needed, can become increasingly proficient at this, even when their cognitive impairments are profound or are progressing. Such persons might articulate values in very concrete terms (e.g., “singing makes me happy” or “I like you”) or indicate them by drawings, gestures or other non-verbal behaviours (such as when a person with dementia recognizes and enjoys a favourite song from youth or a young adult with an intellectual disability claps joyfully to a tune). Those close to such persons, who know them well, can learn to interpret their indications of value reliably.

It is important to clarify that many such indications, namely, those that stem from apprehending values, are not simply *arbitrary choices* without any grounding or context. They are different in kind from whims and fleeting desires, or certain preferences based on these, which every person also has. A contemporary philosopher who elaborates on this morally significant distinction is Michael Bratman (2018). For Bratman, the human will is not just a function of exercising absolute freedom to act or not act (what Lonergan calls the “essential freedom” of human beings). It entails *planning* based on specific ends or values to which a person is committed over time (what Bratman calls “temporally extended intentions”) and is embedded in relating to what others are doing (“shared intentions”). These intentions constitute the ground and context for this person’s decisions and actions and manifests this person’s self-governance or agency.

Can persons with profound intellectual and developmental disabilities have such intentions and manifest such agency? Many caregivers affirm that they can. For instance, Eva Feder Kittay, a philosopher who has a child, Sesha, with a profound intellectual disability, writes thus of Sesha's capacity to apprehend beauty and to share her enjoyment by occasionally turning her head towards her mother with a twinkle in the eye when she likes a particular part of a musical piece: "even with all that Sesha cannot do and seems not to be able to comprehend, her response to music and her sensitivity to people are remarkably intact. Perhaps her responsiveness to music is more than remarkably intact; it is quite simply remarkable." (Kittay, 2008, p. 143)

Interpreting these indications of value in another person, such as Kittay's interpreting Sesha's turning towards her as an intentional activity expressing the value of musical beauty and of company, partly involves being able to discern *the ground or context for that person* of her or his decisions.⁴ This is why reliable interpretations will depend on how close and how well the interpreter knows the person with profound or progressively deteriorating cognitive impairments. The reliability of such interpretations also will develop over time. Moreover, a reliable interpreter can usually discern when a person's decision is not coherent or is misaligned with the authentic values of that person. This type of familiar knowledge of a person resembles the tacit knowledge that Michael Polanyi (1962, p. 4) described. This sort of knowledge cannot be comprehensively explained or easily transferred to others who are unfamiliar with the context of the close relationship.

A further relevant point relates to Bratman's notion of *shared* intentions, which opens up the possibility of shared agency between or among persons.⁴ This brings us to the notion of relational autonomy.

c. Autonomy as relational

Discussions of decision making in health care often refer to the principle of respect for patient autonomy in ethics and law. *Autonomy* has various meanings in these disciplines and in the public's understanding of this term. For instance, some understand autonomy in a way that emphasizes rationality. By *autonomy* they mean an individual's capacity for moral self-governance based on reason and will (Byers, 2016).⁶ For others, autonomy is understood in a way that focuses on individual freedom. By *autonomy* they mean freedom from being interfered with or coerced in matters that are deemed to be private (Rajci, 2016). The former understanding is sometimes referred to as the "positive" sense of autonomy (or the concept of moral agency) and the latter as the "negative" sense of autonomy (or the concept of liberty of action). Still others accept aspects of both meanings. According to either sense of autonomy, however, certain persons whose reasoning or liberty is compromised due to cognitive impairments would be regarded as unable to make autonomous decisions.

These prevailing notions of autonomy in society inadequately attend to *relational* aspects of decision making in persons with and without disabilities. The equation of autonomy with *independence* is not the only way to understand autonomy. When we advert to our experiences of exercising autonomy to make decisions in health care and other areas of life, we *all* depend on others *to some degree* (e.g., to communicate effectively, help with understanding, give guidance or advice, etc.), and in regard to certain decisions more than others. A relational understanding of autonomy most adequately describes our experiences of making decisions.

If we understand autonomy as relational, we can re-conceive decision making as a *capability*, or better, a set of capabilities along the lines of other human capabilities discussed by proponents of the so-called "capabilities approach" in economics, political theory, and social ethics (Senn,

1979, May 22; Nussbaum, 2006). This approach to distributive justice focuses, not on fairness in distributing goods or making opportunities generally available, but on establishing the social conditions that make it *feasible* for each person to access goods and avail themselves of opportunities in society. A just society and a just world should promote human capabilities. *Capability* is a person's functioning in order to enjoy well-being. This includes personal abilities *and* environmental and social conditions to facilitate and support that functioning. When we conceive of making decisions as a set of capabilities, we open up the possibility that each of us might need various types and degrees of assistance from others to *exercise* our autonomy. A clarification, however, should be made. One criticism of the capabilities approach is that it does not go far enough. While it attends to the importance of support from others to exercise capabilities, it does not account for those who might never become self-reliant, even with such support. Reflecting on the reality of human inter-dependency, Eva Feder Kittay comments on the capabilities approach to justice as follows: "[A] theory of justice based on capabilities...does not address dependency head-on and therefore I would argue still needs supplementation with an ethic of care." (Kittay, 2011, p. 51) We add also that it needs to be supplemented by an understanding of autonomy as relational, as discussed above. It could be that some persons might need decision-making supporters, not simply to help them to interpret their authentic values, but also to *decide* (e.g., for their supporters to select from among treatment options those that most align with these values). From an understanding of autonomy as relational and inter-dependent, such persons can be recognized as exercising relational autonomy.

d. respect for autonomy and other ethical principles in health care

In contemporary bioethics, health law, and health care, there is a tendency to regard respect for a person's autonomy as the sole or primary consideration. This trend calls into question, what is referred to as *paternalism* in healthcare decision making, e.g., when authority figures (e.g., healthcare professionals or parents of adult patients with intellectual and developmental disabilities) decide on treatments, either without involving the person in making the decision or despite the person's refusal of a treatment. Some bioethicists consider as "soft paternalism" instances in which healthcare providers persuade ("nudge") persons to accept treatments that they need (Sunstein & Thaler, 2003; Blumenthal-Barby & Burroughs, 2012; Verweij & van der Hoven, 2012).

Criticisms of so-called paternalistic approaches in healthcare decision making can be valid; sometimes, however, they are based on an inadequate understanding of autonomy that equates autonomy with absolute independence. Also, those who reject paternalism in healthcare decision making often set up a false opposition between respecting a person's autonomy and other ethical principles such as beneficence, non-maleficence, and solidarity. It is beyond the scope of this paper to examine in detail the issue of involuntary treatments in health care, especially mental health care. For our purposes, it suffices to say that there can be approaches to providing treatments that would be both beneficial to persons in need of health care (or would reduce the risk of them being harmed) *and* support and promote the decision-making capabilities of such persons and their exercise of autonomy. Indeed, no treatment can be truly beneficent, non-maleficent or promote solidarity with a person if it is simply imposed without effort to include the person in the health care planning process (Sullivan, Heng, DeBono et al., 2020, recommendation 3(a), p. 364). What practical implications for health care does this philosophical and ethical framework for supported decision making have?

III. Applying theory to practice in health care

a. Assessing decision-making capacity

Most criteria for assessing decision-making capacity in health care establish *thresholds* for determining whether this capacity is present or absent in a person for a certain decision. These criteria set up a binary distinction: either the person can authorize the decision (because she or he is capable or competent), or the person cannot. If a supported decision-making approach is accepted, however, the focus of such capacity assessments will need to change.

First, we would have to acknowledge that a person's decision-making capabilities exist on a continuum for each of those capabilities (e.g., the operations in human knowing described by Bernard Lonergan).

Second, in assessing decision-making capacity, the focus is often only on those cognitive operations thought necessary for giving *informed* consent. Typically, the person must demonstrate being able to understand information relevant to proposed treatments and appreciate the consequences of being treated or not treated (i.e., what Lonergan described as the second and third operations in human knowing). In a supported decision-making approach, however, the pivotal step in healthcare decision making is to discern a person with intellectual and developmental disabilities' values or what matters fundamentally to her or him. Here, the capacity to be assessed is the person's ability to hold and express such values in a way that at least one other person can validly understand. This is the basis for someone to help the person with intellectual and developmental disabilities to select, from among offered healthcare options, the one most able to realize those values (the fourth operation in human knowing for Lonergan).

Third, a supported decision-making approach would recognize and affirm relational autonomy. This would have two implications: the focus of assessments of decision-making capabilities would include identifying supports that patients might need for any of the capabilities involved in making healthcare decisions. If it is determined that persons with intellectual and developmental disabilities are capable of expressing their authentic values, even if they might sometimes require help from close and trusted decision-making supporters who know them well for other aspects of the healthcare decision-making process, their decisions with such support should be recognized as authoritative.

Making such assessments will not always be straightforward and will entail some modifications of usual practice and skills. However, some aspects of a supported decision-making approach to assessing capacity in health care are often already informally practised in person- and family-centred health care. The central principles underlying good assessments of patients should hold in any context: strive to know the patient and caregivers well, and build good relationships based on effective communication and trust.



Since applying supported decision making in health care is recent, there are few tools to guide healthcare providers in assessing adults with intellectual and developmental disabilities using this approach. *Decision making in health care of adults with intellectual and developmental disabilities: promoting capabilities* (Sullivan, Heng, Bach et al. 2020), to our knowledge, is the only such tool that has been developed. This tool is designed mainly for use in the province of Ontario, Canada, where only legally recognized substitute decision-makers can provide consent to treatment for persons assessed to lack decision-making capacity. In this regard, Ontario has a legal regime that is not yet aligned with what is required of Canada and other states that have ratified the *UNCRPD* (2006); however, the help of decision-making supporters to enable adults

with intellectual and developmental disabilities to meet the criteria for legal decision-making capacity in Ontario may be considered a reasonable accommodation under the province's human rights laws. Substitute decision makers who do not know the person who is assessed to lack decision-making capacity well can also be encouraged to consult with persons who can reliably interpret the person's health-related goals and values. Hence, there can be legal recognition of supported decision making within these limits.

The *Decision making in health care of adults with intellectual and developmental disabilities: promoting capabilities* tool guides healthcare providers to determine which decision-making approach is appropriate to take with an adult with intellectual and developmental disability: an independent, inter-dependent (i.e., supported), or substituted approach. Including the inter-dependent or supported approach broadens the spectrum of adults with intellectual and developmental disabilities who can authorize healthcare decisions. The collaboration between the adult with intellectual and developmental disabilities, with supports as needed, and the healthcare provider to reach agreed-upon goals of care is what we understand by shared decision making.

Figure 1

Decision-making approaches across a spectrum of capabilities of adults with intellectual and developmental disabilities (Sullivan, Heng, & Bach, 2020).

 PATIENT IS CAPABLE OF MAKING THE DECISION		 PATIENT IS INCAPABLE OF MAKING THE DECISION
INDEPENDENT The patient can provide appropriate information to the healthcare provider performing the capacity assessment without the assistance of a decision-making supporter to meet the capacity test.	INTER-DEPENDENT In order to optimize the patient's ability to best demonstrate that they meet the test for legal capacity, the patient requires the accommodation of having a decision-making supporter present to help the patient respond to the healthcare provider performing the capacity assessment.	SUBSTITUTED Even with help from a decision-making supporter and other supports, the patient is unable to respond to assessment questions to meet the capacity test. The patient will require a substitute decision-maker.

b. Promoting conditions to optimize communication with the person in need of health care

The above-mentioned tool prompts healthcare providers to explore various means to optimize communication with the person with intellectual and developmental disabilities in need of health care. It is important that the healthcare provider adapts communication to the person's preferred communication method and asks the person whether she or he wishes to involve caregivers or others to whom the person is close and whom the person can trust to be a decision-making supporter.

Certain accommodations that are not usually considered should be offered to adults with intellectual and developmental disabilities, for instance: Scheduling appointments at an optimal time of day for the person, booking sufficient clinic time, and making the environment appropriate to put the person at ease (e.g., by accommodating any noise or light sensitivities the person might have).

Healthcare providers should be aware that some patients with intellectual and developmental disabilities have difficulty expressing emotional distress related to their illness, past traumatic experience with health care, and other negative life events that could unduly influence their

decisions to refuse certain proposed interventions. When being assessed, the patient's distress might be manifested by resistance or lack of engagement. The underlying causes of such behaviour need to be identified and assiduously explored.

For instance, consider the circumstances of a young woman with intellectual and developmental disability in the severe range, Miriam, who is prone to developing pneumonia. Miriam has a small range of single words that she can use but she prefers to communicate mostly by gesturing and pointing. She also is very sensitive to intense lights and noise. Miriam lives in a group home where she is susceptible to a high rate of influenza (flu) transmission. Prior to that, between the ages of 5 and 25 years old, she had lived in an institution for persons with intellectual and developmental disabilities. Her family has had little involvement in her life since she lived in that institution or the group home, however, her older brother, under the law, would be her substitute decision maker if Miriam was assessed to lack decision-making capacity for a certain health decision. Miriam is usually accompanied to the primary care office by her group home worker, Ingrid, who has known her well for ten years. This year, because of the COVID-19 pandemic, public health authorities have strongly advised that people receive flu and pneumococcal vaccines if they have a high risk of developing pneumonias. Ingrid explains this to Miriam, and Miriam agrees to visit her new family physician for these vaccinations. Before the visit, the physician consults with Ingrid about needed accommodations for Miriam and schedules an appointment early in the day when Miriam is usually calm and there are few people in the clinic. After developing rapport with Miriam, the physician asks whether she would like Ingrid to remain in the room. She indicates "yes" with a nod. When the physician brings up the issue of the vaccinations with Miriam during the visit, she seems initially confused. Ingrid helps to remind Miriam of what they had previously discussed regarding the vaccinations, and she seems

to understand; however, when the physician brings out the needles, Miriam manifests agitation. The physician demonstrates the injection procedure on herself. Miriam remains distressed and shakes her head repeatedly when the physician asks if she may do the same to her. The physician asks Ingrid about this distress. Ingrid maintains that Miriam had agreed to come to the office to be vaccinated when they had discussed this previously. Upon further exploration with Ingrid, the physician discerns that Miriam had some traumatic healthcare experiences while she lived in the institution. The physician manages to calm Miriam and explain to her that these injections will help her to keep healthy and enable her to do the activities she enjoys. Ingrid repeats this message to Miriam. The physician then offers Miriam the option of flu vaccination by a nasal spray, which she accepts, and schedules another visit for the pneumococcal vaccine injection, which can be administered by injection following desensitization training.

In this scenario, the physician is assessing Miriam's capacity to make a certain healthcare decision through optimizing communication and involving a decision-making supporter who knows Miriam well and is trusted by her. She avoids assuming that Miriam is incapable of making any healthcare decision because of the severity of her intellectual and communicative impairments and contacting her substitute decision maker for consent for the vaccinations, which in Miriam's case would be her uninvolved older brother. She also avoids assuming that Miriam is capable of making this healthcare decision independently. She asks Miriam whether she would like Ingrid to support her in making this decision. Ingrid helps Miriam to communicate with the physician, and vice versa. With the help of Ingrid, the physician is able to discern that Miriam's initial resistance to the injections was likely motivated by strong responses to the trauma of her past healthcare experiences, and that Miriam also wished to avoid the risk of developing a severe illness that would undermine what she enjoys in life. This involves the physician distinguishing

between Miriam's spontaneous response to a dissatisfaction and her responses to values, i.e., those things Miriam truly hopes for and values.

c. Supported decision making and shared decision making

In the above scenario, it is true, the physician is offering the sort of shared decision making that should be practised with *any* person in need of health care. Shared decision making, however, can sometimes be construed according to a consumer model of health care in which persons are assumed to be independent agents capable of negotiating health care with physicians as equals. A supported decision-making approach emphasizes relational autonomy and the importance of offering accommodations and supports in healthcare decision making to adults with intellectual and developmental disabilities as needed, such as by offering an alternative means of flu vaccination in Miriam's circumstance. Miriam, however, would not have been able to assess independently the benefits and risks of vaccination via nasal spray versus injection. She still needed the support of Ingrid and her physician to help her interpret their relative risks, benefits, and burdens to her in terms of her health goals (to stay healthy), values (what she enjoys in life), and preferences (benefits without being traumatized by an injection).

From a supported decision-making approach, the healthcare provider should always endeavour to engage patients in the decision-making process regarding their care and include any decision-making supporters whose help a patient needs and wants. They should ensure that patients understand that there are options for care, that they can draw on help from their decision-making supporters at any time, and that a decision does not have to be made during a single visit.

Miriam's physician, for example, defers the decision regarding the pneumococcal vaccine injection until a scheduled follow-up visit.

The scenario involving Miriam illustrates that healthcare providers also have some role in supporting decision-making capabilities of patients and the patient's decision-making supporters. It is ethically appropriate for healthcare providers not only to give factual information regarding possible interventions and their potential benefits, burdens, and risks. They should also be prepared to elicit and discuss the authentic values of patients, with the help of decision-making supporters as needed, and relate these values to health-related goals underlying various treatment options (e.g., prolonging life, improving function, alleviating distress, fostering important relationships, minimizing burdens for the patient and patient's family).

The healthcare provider should also be aware of and accommodate any cultural or religious perspectives regarding decision making in health care. For example, in certain cultural or religious traditions, respect for those in authority in the family or in health care might be accepted and expected by the person with intellectual and developmental disabilities. In such situations, a greater role can be given to the decision-making support of family members whom the person values and trusts.

Above all, it is important in shared decision making to strive for common goals of care among patients, the caregivers on whom they depend, and healthcare providers. Prudent judgments by healthcare providers can often facilitate agreements. For example, when a treatment option involves uncertainty or ambiguity, a trial period for intervention might be an acceptable option to all. At other times, the healthcare provider might need to address concerns or reservations of patients by accepting a less medically effective option. For example, in the circumstance of Miriam above, flu vaccination via a nasal spray, while possibly less effective, can often be an acceptable alternative, along with other therapies in the long term to address Miriam's fears concerning needles.

In summary, shared decision making is important for healthcare providers to offer as part of patient-centred care, regardless of whether the adult with intellectual and developmental disabilities is assessed to be capable independently or inter-dependently (i.e., with the help of one or more decision-making supporters) of reaching a certain healthcare decision or requires a substitute decision-maker.

Conclusion

Patients with intellectual and developmental disabilities are capable of apprehending, holding and expressing authentic values. As with any patient, these should guide decision making regarding their health care. Many such patients might also require decision-making supporters to help with some part of the decision-making process, e.g., understanding, judging, interpreting their authentic values or deciding with them on acceptable options for treatment. Autonomy is relational. We all need various types or degrees of help from others, for certain kinds of decisions more than others. When needed, help from decision-making supporters and healthcare providers can promote an adult with developmental disabilities' decision-making capabilities and exercising relational autonomy. Ways should be found to respect the goals and authentic values of persons while providing them with treatments that are beneficial to them or would reduce the risk of them being harmed.

There remain further questions regarding supported decision making in health care. For example, what can and should be done to promote the decision-making capabilities of those patients who cannot decide independently but have no close persons who know them well enough to interpret their authentic values? What impact would supported decision making have on caregivers and other decision-making supporters who often have inadequate guidance, coaching, and other

resources for their role? What safeguards would have to be in place to ensure that decision-making supporters undertake their role responsibly and ethically? Do healthcare providers have an ethical responsibility to advocate for policy and social changes, to legally recognize supported decision-making approaches in health care and to foster the kinds of close relationships that socially isolated persons with intellectual and developmental disabilities need to support them in making healthcare decisions?

While continuing to address questions such as these, we can nonetheless conclude that supported decision-making approaches affirm the inherent dignity of patients with intellectual and developmental disabilities, will enhance their participating in making healthcare decisions with supports as needed, and can enable their authority to make those decisions to be ethically and legally recognized.

END NOTES

1. For example, youth with intellectual and developmental disabilities might have few friends beyond family members and staff. They often experience barriers to communicating, stigma and neglect by other persons, and bullying. Family and staff often control whom they associate with and how that time is spent. Their friendships are usually formed in the context of structured activities programmed by caregivers and staff. Poverty can also lead to fewer opportunities for socializing.
2. There are different reasons for health disparities, e.g., barriers to communicating and stigma, which make it less likely for persons with intellectual and developmental disabilities to report symptoms or seek health care and health promotion programs. Also, healthcare providers might

fail to recognize the specific health needs of these patients or be reluctant to take on patients with such complex health needs.

3. Lonergan brings an important line of thinking in Western philosophy regarding practical wisdom and virtue, e.g., in the works of Aristotle and Aquinas, into conversation with 19th- and 20th-century existentialist thought, which emphasize the free self-making of human beings through their decisions and actions. Lonergan conceives of this freedom, not as absolute freedom, but as freedom to respond or not to a certain basic human orientation towards what truly will bring about well-being as a whole person and fulfillment. He retains the Aristotelian and Thomistic idea that ethics is about practical wisdom, which always pertains to concrete decisions and actions and not abstract principles, and the idea that virtue is a state of human character concerned with choice. In other words, discussions of virtue and vice in ethics cannot be considered apart from considering what moral subjects decide and do.

4. See the discussion on will (especially how a Kantian understanding is different from a Cartesian understanding of will) in Szmukler (2017, p. 93).

5. Here we note that Michael Bratman's account of intention relates to what he calls "practical rationality" whereas Bernard Lonergan, at least in his later writings after *Method in theology*, would attend to the importance of affective cognitions for practical and moral knowledge, as explained above. Then, for Lonergan, a shared intention (in Bratman's sense) would entail enmeshment of not only one or more shared values between or among persons but also the possibility of shared *affective cognitions* (shared feelings) underlying those values. To develop this idea is beyond the scope of this paper but might include considering the insights of Edith Stein on intersubjectivity. See, for example, Stein (1989).

6. An example would be *autonomy* as understood by the philosopher Immanuel Kant. The duty to respect another person's autonomy, according to a Kantian understanding of autonomy, derives from "shared humanity" among persons who, individually and equally, are rational and self-governing. Such persons, according to Kant, ought always to be treated as ends in themselves and not mere means to other people's ends.

REFERENCES

- Anderson, J., Honneth, A. (2005). Autonomy, vulnerability, recognition, and justice. In Christman, J. & Anderson, J. (Eds.). *Autonomy and the challenges to liberalism: New essays*. Cambridge: Cambridge University Press, 127-149.
- Anscombe, G.E.M. (1958). *Intention*. Oxford, UK: Oxford University Press.
- Bach, M. & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity: Advancing substantive equality for persons with disabilities through law, policy and practice*. Toronto: Law Commission of Ontario. <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf>.
- Blumenthal-Barby, J. S. & Burroughs, H. (2012). Seeking better health care outcomes: The ethics of using the "nudge." *American Journal of Bioethics*, 12(2): 1–10.
- Bratman, M. E. (2018). Agency, time, and sociality. In: Bratman, M. E. (Ed.). *Planning, time, and self governance: Essays in practical rationality*. New York, N.Y.: Oxford University Press, 110-130.
- Brucker, D. L. & Nord, D. (2016). Food insecurity among young adults with intellectual and developmental disabilities in the United States: Evidence from the National Health Interview Survey. *American Journal on Intellectual and Developmental Disabilities*, 121(6), 520-532.

- Byers, P. (2016). Dependence and a Kantian conception of dignity as a value. *Theoretical Medicine and Bioethics*, 37, 61-69.
- Byrne, G. (2018). Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities: JOID*, 22(3): 294-310.
- Cole, A. (2019, Sept. 4). Presentation to PROBUS, Perth, Ontario, Canada.
- Dahlsgaard, K., Peterson, C., Seligman, M. E. P. (2005). Shared virtue: The convergence of shared human strengths across cultures and history. *Review of General Psychology*, 9(3): 203-213.
- Davidson, G., Kelly, B., MacDonald, G., et al. (2015). Supported decision making: a review of the international literature. *International Journal of Law and Psychiatry* 2015, 38, 61–67.
- Dinerstein, R. D. (2012). Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making. *Human Rights Brief*, 19(2), 8-12.
- http://www.supporteddecisionmaking.org/sites/default/files/implementing_legal_capacity_article_12_un_convention.pdf.
- Finnis, J. (1980; 2011) *Natural law and natural rights*. Oxford: Oxford University Press.
- Frankfurt, H. (1999). Necessity, volition and love. Cambridge, U. K.: Cambridge University Press, essays 9, 11 & 14.
- Honneth, A. (2007). *Disrespect: The normative foundations of critical theory*. Cambridge, U. K.: Polity Press.

- Hoole, L. & Morgan, S. (2011) 'It's only right that we get involved': Service-user perspectives on involvement in learning disability services. *British Journal of Learning Disabilities*, 39(1), 5–10.
- Hughes, K., Bellis, M. A., Jones, L., et al. (2012) Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, 379(9826):1621-9.
- Hughes-McCormack, L. A., Rydzewska, E., Henderson, A., et al. (2018). Prevalence and general health status of people with intellectual disabilities in Scotland: A total population study. *Journal of Epidemiology and Community Health*, 72, 78-85.
- Hurd C., Evans, C., Renwick, R. (2018). "Having friends is like having marshmallows": Perspectives of transition-aged youths with intellectual and developmental disabilities on friendship. *Journal of Applied Research in Intellectual Disabilities*, 31(6): 1186-1196.
- Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, 24(1): 49-58.
- Lonergan, B. (1972; 1988). In Doran, R.M. & Dadovsky, J. D. (Eds.). *Method in theology. Collected works of Lonergan, volume 14*. Toronto: University of Toronto Press, 1988.
- Lonergan, B. (1996). The subject. In: Ryan, W. F. J. & Tyrrell, B. J. (Eds.). *A second collection: Papers by Bernard J.F. Lonergan. 2nd ed. Collected works of Lonergan, volume 11*. Toronto: University of Toronto Press, 69-78.
- Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, 50(1), 370-396.
- Nussbaum, M. (2006). *Frontiers of justice: Disability, nationality, species membership*. Cambridge, M.A.: Harvard University Press, Belknap Press.
- Polanyi, M. (1962). *The tacit dimension*. New York, N. Y.: Anchor Books.

- Potvin, L. A., Fulford, C., Ouellette-Kuntz, H., et al. (2019). What adults with intellectual and developmental disabilities say they need to access annual health examinations: System navigation and person-centred care. *Canadian Family Physician*, 65(Suppl. 1), S47-S52.
- Rajczi, A. (2016). Liberalism and public health ethics. *Bioethics*, 30(2), 96-108.
- Sen, A. (1979, May 22). Equality of what? The Stanford University Tanner lecture on human values, May 22, 1979. https://tannerlectures.utah.edu/_documents/a-to-z/s/sen80.pdf.
- Simmons, M. & Gooding, P. (2017). Spot the difference: Shared decision-making and supported decision-making in mental health. *Irish Journal of Psychological Medicine*, 34(4), 275-286.
- Stein, E. (1989). *On the problem of empathy*. Stein, W. (Ed.). *The Collected Works of Edith Stein, volume 3*. Washington, D. C.: ICS Publications.
- Sullivan, W. F. (2005). *Eye of the heart: Knowing the human good in the euthanasia debate*. Toronto: University of Toronto Press.
- Sullivan, W. F., Diepstra, H., Heng, J., et al. (2018). Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Canadian Family Physician*, 64(4), 254-279.
- Sullivan, W. F. & Heng, J. (2018). Supporting adults with intellectual and developmental disabilities to participate in health care decision making. *Canadian Family Physician*, 64(Suppl 2): S32-S36.
- Sullivan, W. F., Heng, J., Bach, M., et al. (2020). *Decision making in health care of adults with intellectual and developmental disabilities: promoting capabilities*. Toronto: Developmental Disabilities Primary Care Program, Surrey Place. <https://ddprimarycare.surreyplace.ca/tools-2/general-health/capacity-for-decision-making/>

Sullivan, W. F., Heng, J., DeBono, C., et al. (2020). Promoting capabilities to make healthcare decisions. Consensus Statement of the 9th IACB International Colloquium. *National Catholic Bioethics Quarterly* 2020, 20(2), 617-633.

Sulmasy, D. P. & Snyder, L. (2010) Substituted interests and best judgments: An integrated model of surrogate decision making. *Journal of the American Medical Association (JAMA)*, 304(12): 1946-7.

Sunstein, C. & Thaler, R. (2003) Libertarian paternalism is not an oxymoron. *University of Chicago Law Review*, 70, 1159–1202.

Szmukler, G. (2017). The U.N. Convention on the Rights of Persons with Disabilities: ‘Rights, will and preferences’ in relation to mental health disabilities. *International Journal of Law and Psychiatry* 54, 90-97.

The Mental Capacity Act (U. K.) (2005) <https://www.legislation.gov.uk/ukpga/2005/9/section/4>.

Topor, A., Ljungqvist, I., Strandberg, E. (2016). The costs of friendship: severe mental illness, poverty and social isolation. *Psychosis*, 8(4), 336-345.

United Nations (2006). *Convention on the rights of people with disabilities*. New York, N. Y.: United Nations, articles 12(1) and 12(3).

<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.

United Nations Committee on the Rights of Persons with Disabilities (2014). *General Comment no. 1*. Geneva: United Nations; 2014. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf>.

Verweij, M. & van den Hoven, M. (2012). Nudges in public health: Paternalism is paramount. *American Journal of Bioethics*, 12(2), 15-17. Williamson, H. J., Contreras, G. M., Rodriguez, E.

S., et al. (2017). Health care access for adults with intellectual and developmental disabilities: A scoping review. *OTJR: Occupation, Participation and Health*, 37(4), 227-236.