Child Capacity and Participation in Healthcare Decisions

The Society for Children and Youth of BC

SOCIETY FOR children and youth OF BC

REPRESENTATIVE FOR CHILDREN AND YOUTH

Health Care

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The Society for Children and Youth of BC would like to acknowledge that we live and work on the traditional territories of the First Nations peoples of British Columbia. Our office is located on the Unceded Territory of the xʷməθkwəy̓əm (Musqueam), sḵwx̱wú7mesh (Squamish) and səl̓ilwətaʔɬ (Tsleil-Waututh) First Nations. We express our sincerest gratitude to the custodians of these lands and beyond across BC. We also wish to recognize the specific impacts on Indigenous Peoples and communities that are a result of the systems that are the focus of these papers. We invite readers to critically engage with the themes and key findings presented using this lens as well as an intersectional approach to take action.

Finally, we would like to acknowledge the invaluable contribution of the Office of the Representative for Children and Youth in facilitating this research. Their expertise, insights, and guidance throughout the research process were instrumental in shaping this work.

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About The Society for Children and Youth of BC

The Society for Children and Youth of BC (SCY) is a provincial not-for-profit charity. Since 1974, the Society has focused on providing a strong voice representing children and youth. Our mission is to improve the well-being and resilience of children and youth in BC through the advancement of their civic, political, economic, social, cultural and legal rights. Using the UN Convention on the Rights of the Child as a foundation, SCY has a track record of creating and delivering programs that have motivated change in research, legislation, policy, and practice in Canada. This year, we proudly celebrate 50 years of advocacy for child and youth rights. The organization is comprised of three programming areas: The Child and Youth Legal Centre, Child and Youth Friendly Communities, and Child Rights Public Awareness.

The Child and Youth Legal Centre (CYLC), established in 2017, provides free support to young people experiencing issues related to Family Law, Child Protection, human rights violations, and other legal matters. The Legal Centre is made up of Lawyers, Intake Workers, Child and Youth Advocates and a Social Worker. The Legal Centre has seen significant growth since its inception, and in 2023 supported 1125 young people across 90+ Communities in British Columbia.

SCY's Child and Youth Friendly Communities (CYFC) program supports child-friendly community-building with young people. Over the past eight years we have worked in collaboration with various Metro Vancouver municipal planning teams to ensure that children and youth have a stronger voice in their community's planning initiatives. Our aim is to ensure that public engagement is a deep and meaningful experience for

young people. Some of our projects include the Walking School Bus, School Streets, Play Streets, and Urban Explorers.

The Child Rights Public Awareness Campaign began in 2006 when SCY, the Representative for Children and Youth, and the Institute for Safe Schools of BC came together to envision a plan for raising awareness of child rights. Throughout the years, the campaign has engaged in numerous activities including roundtables on children's rights, the creation of a child rights network, a multimedia campaign, community and youth engagement activities, and the development and dissemination of child rights resources across the province, including multilingual resources.

Drawing from our experiences over the past several decades across different sectors advocating for child and youth rights, SCY conducted a Child Capacity Research Project as commissioned by the Representative for Children and Youth of B.C. This work aims to highlight the importance of child participation rights by way of research papers on child capacity in the context of four key areas: 1) family law, 2) child welfare and adoptions, 3) decisions about healthcare, and 4) mental health and involuntary civil detention. We are pleased to present this report series as it reflects a culmination of comprehensive literature analysis and multi-faceted youth engagement specific to each area. It is our hope that the key findings identified within each paper will support systemic action and facilitate cross-sectoral collaboration within B.C.

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Child Capacity and Participation in Healthcare Decisions

Society of Children and Youth of BC
Lisa Maria Bellano

"
The biggest issue was that no one would listen to me. No one. There was no one listening.

A. Executive Summary

This paper is part of a series on the topic of child capacity in relation to child participation rights. Throughout this collection of papers, we focus on the following areas: a broader socio-legal discussion on child capacity; family law; child welfare and adoptions; mental health and involuntary civil detention; and decisions about health care.

The key findings of this paper are derived from a literature review, legal analysis, and youth engagement. The youth engagement included surveys, interviews, and listening circles with children and youth regarding their experiences of capacity in the context of decisions about healthcare. The Society for Children and Youth of BC want to acknowledge the thoughtful young people who spoke candidly about their lived experiences. Those voices are critical to the research and key findings.

Key Findings

1. Regardless of their decision-making abilities, all children and youth have a right to be heard and to express their views in decisions concerning their healthcare.

2. As in adults, capacity of children and youth encompasses a variety of factors and develops at different rates. It is an evolving trait that may be more or less present in different contexts and can be assessed through a variety of models available to healthcare providers.

3. Healthcare must be patient-centred, with the views and interests of the young patient meaningfully considered in the provision of services. The onus must be on the healthcare provider to find an effective strategy to communicate and connect with their child or youth patient.

4. Dismissal and invalidation by healthcare providers, parents, and other adults contributes to significant negative impacts on children and youth including reduced self-esteem and confidence in their treatment plans.

5. Children and youth would greatly benefit from neutral, third-party support in medical settings that focuses only on their interests, needs, and views.

6. For many children and youth, making healthcare decisions can be an empowering experience, helping them develop individual agency.

B. Background and purpose of report

This paper provides an overview of the legal framework governing children and youth's capacity and participation in healthcare decision-making within Canada, contextualized within a broader children's rights framework informed by the United Nations Convention on the Rights of the Child (UNCRC), particularly Articles 5 and 12. Focused primarily on the jurisdiction of British Columbia, this paper explores the interplay of legal principles, provincial statutes, and international conventions, providing an overview of the way in which these elements interact to shape healthcare decision-making processes for minors. By contextualizing legal principles within a children's rights framework informed by the UNCRC, this paper seeks to contribute to a deeper understanding of the complex dynamics shaping healthcare decision-making processes for minors and the importance of upholding children's participatory rights in healthcare contexts.

This paper is part of a larger research project exploring the interplay between child capacity and child participation in legal proceedings in Canada with a focus on the experience of children in British Columbia. Capacity and participation are considered through the lens of the United Nations Convention on the Rights of the Child (UNCRC) (1989), to which Canada is a signatory, and the Canadian Charter of Rights and Freedoms.

C. Discussion

Legal framework and concepts

> *"I don't think age had anything to do with capacity. I will say our age has something to do with what other people think of our capacity. I know minors are not exactly allowed to make certain decisions. I felt like my age had something to do with the first time. I felt the second time I should speak up, because I am older."*
>
> Youth Engagement

In Canada, the framework for children or youth to exercise their capacity to make healthcare decisions is complex, in large part due to the interplay between common law principles, provincial and territorial legislation, child protection laws, legal precedents, and international conventions.

- The mature minor doctrine, which recognizes the capacity for children to make health care decisions for themselves, grants some autonomy to mature children and youth to make their own treatment choices, even when those choices don't align with those of their guardians.
- Some provincial and territorial laws set specific ages at which children can consent to medical procedures, although many do not provide specific ages and instead offer factors for consideration.
- Child protection legislation allows agencies to seek court orders for treatment if consent is refused by the child or parent, prioritizing the child's well-being.
- Legal precedents guide the interaction of these laws, shaping healthcare decision-

making for children and youth across Canada.

- The United Nations Convention on the Rights of the Child intersects with Canada's legal framework for children's healthcare decisions by reinforcing the rights of children to participate in matters concerning their health and well-being, while the Nuremberg Code provides the fundamental basis for the right of a person to consent to medical treatment. The World Health Organization provides guidance on the topic of child and youth capacity in the context of healthcare decisions.

The Evolving Trait of Capacity

> *"I think of capacity as my ability to do something, taking into account my resources and support. When I make a decision, I have the capacity to do so if my resources and support allows me to. This can be as simple as having a safe space to sit and think something through, or talk a decision out with someone."*
>
> Youth Engagement

Capacity is widely recognized as an evolving rather than fixed trait; that is, a "fluid and evolving response to various situations" (Henderson, 2022, p.6). This further supports the premise that children are also "active agents in their own lives entitled to be listened to, respected and granted increasing autonomy in the exercise of rights, while also being entitled to protection in accordance with their relative immaturity and youth" (Lansdown, 2005, p.ix; Bellano, 2024, p. 14).

In their toolkit for health care providers, the World Health Organization (WHO, 2021) provides a guide for assessing and supporting young people's capacity to make decisions in health care. Some of the definitions of the key concepts are:

A) **Competence:** WHO defines competence as a legal concept "referring to the right to make an autonomous decision (i.e. a decision taken without authorization by a third party, e.g. parents or guardian)" (2021, p. v). Whether a person is considered to be legally competent is determined by the laws of each nation. WHO notes that in some countries, "minor adolescents are considered competent as long as, in a given situation, their health-care providers consider that they are capable of decision-making" (2021, p. v). In other countries, competence is more strictly defined by the age of the young person.

B) **Decision-making capacity:** WHO distinguishes between competence and decision-making capacity. According to WHO, competence is a legal concept; decision-making capacity, conversely, is a "clinical concept that refers to the individual psychological or cognitive ability to make a decision" (2021, p. v). WHO outlines four separate dimensions that constitute decision-making capacity: (1) how a person understands information pertaining to their condition and the available treatment options; (2) how a person compares treatment options by "balancing risks and benefits", and their ability to discuss the "potential consequences" of any given decision; (3) how a person "discusses the relevance of the options for

their own situation"; and (4) how a person expresses a choice and argues for it in "light of previous discussions" (2021, p. v).

C) **Evolving capacity:** Consistent with the UNCRC, WHO advances an overall definition of child and youth capacity as evolving. This refers to the evolving or changing capacity of an adolescent to "understand matters that affect changes in their life and health with age and maturity" (2021, p. v). Specifically, "the more an adolescent knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for him or her can transform direction and guidance into reminders and advice, and later into exchange on an equal footing" (2021, p. v). In the healthcare context, evolving capacity means that as a child or youth matures, their views are accorded increasing weight in healthcare choices. Neither age nor vulnerability (such as having a disability or belonging to a minority group) prevent a child or youth from exercising their evolving capacity—these are not appropriate bases to "deprive them of the right to express their views, nor does it reduce the weight given to the adolescent's views in determining their best interests and, hence, choices on aspects of care" (2021, p. v).

D) **Informed choice:** WHO defines informed choice as one made "on the elements of [one's] care", including "treatment options, follow-up options, refusal of services" and arising "as a result of adequate, appropriate, clear information for understanding the nature, risks, alternatives to a medical procedure or treatment and their implications for health and other aspects of the adolescent's life" (2021, p. vi). In a situation where there are multiple possible courses of action for a health condition, or in the presence of treatment uncertainty, then "the advantages of all possible options must be weighed against all possible risks and side-effects" (2021, p. vi). In all cases, the views of the child or youth "must be given due weight according to his or her age and maturity" (2021, p. vi).

E) **Informed consent:** Informed consent is defined by WHO as "a documented (usually written) agreement or permission based on full, clear information on the nature, risks and alternatives of a medical procedure or treatment and their implications, before the physician or other [healthcare provider] begins the procedure or treatment" (2021, p. vi). After this information is received, the child or youth, or third party authorized to give informed consent, may either consent to or refuse the procedure or treatment. As WHO explains, laws vary state-by-state in terms of which procedures or treatments require informed consent. Once again aligning with the UNCRC, WHO provides that an adolescent "should be supported to make an informed choice and give assent if they wish" (2021, p. vi).

As noted above, WHO notes that competence must be differentiated from capacity: competence pertains to a legal concept respecting "the right to provide an opinion or make an autonomous decision", while capacity refers to a "clinical concept of individual

psychological and cognitive ability to understand information, reason and reflect to make a decision" (2021, p. 6). Both are "task- and context-specific" (WHO, 2021, p. 6), meaning that the competence and capacity that are required shift according to the task or context at hand. In terms of children and youth, WHO explains that a potential difficulty is the fact that "capacity for autonomy is a continuous variable (evolving degree of capacity), but determination of competence is dichotomous (yes or no)" (2021, p. 6). This means that capacity is a shifting or evolving variable, but competency either is or is not required for a task or situation.

WHO further notes that, since capacity is "specific to each task and context specific, adolescents may have adequate capacity for a given decision but diminished or absent capacity for another medical decision" (2021, p. 6).

Capacity is also widely referenced in the UN Convention on the Rights of the Child (the UNCRC). Article 5 of the UNCRC states that "States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, **in a manner consistent with the evolving capacities of the child**, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention" (emphasis added).

The UNCRC does not provide a definition of capacity. According to Henderson-Dekort and colleagues (2022):

> Within specific articles within the United Nations Convention on the Rights of the Child (1989), it is clear that there is frequent uncertainty surrounding the term capacity. It remains a difficult concept to assess with certainty, especially in the case of children. This is concerning considering how frequently the term is used or alluded to in matters that pertain to the participation or rights of children (p. 3).

"Evolving capacity," as it is used in Article 5 of the UNCRC, refers to a child's progressive ability to exercise his or her rights (Canadian Bar Association, CBA, 2023). This is distinct from the view that capacity is a fixed trait. Instead, the evolving capacity viewpoint provides that capacity is not fixed, but rather is a "fluid and evolving response to various situations"—it is situation and context-dependent (Alderson & Goodwin, 1993). More to this point, evolving capacities recognizes children as "active agents in their own lives, entitled to be listened to, respected and granted increasing autonomy in the exercise of rights, while also being entitled to protection in accordance with their relative immaturity and youth" (Lansdown, 2005, p. ix).

Article 12(1) of the Convention stipulates that States Parties provide a child **"capable of forming his or her own views the right to express those views freely in all matters affecting the child"**, and that the **child's views be given due weight in accordance with the child's age and maturity** (emphasis added). Article 12(2) further states that the child be provided an "opportunity to be heard in any judicial and administrative proceedings" affecting him or her, "either directly, or through a representative...

in a manner consistent with the procedural rules of national law". Again, this article references a developmental view of capacity, providing that as children develop and acquire capacity, they shall become entitled to higher levels of responsibility in areas that affect them (UN General Comment No. 12, 2009, para. 85).

Further, The Nuremberg Code (1947) serves as a fundamental framework for consent in healthcare decisions, emphasizing voluntary participation and informed, uncoerced agreement. Though not explicitly mentioning children and youth, its principles apply to them implicitly, affirming their right to make informed healthcare choices (Annas & Grodin, 1992). It defines consent as the voluntary, informed agreement of an individual to participate in medical procedures, stressing the importance of safeguarding individuals from coercion or exploitation.

Presumption of Capacity or Competence

While adults are legally presumed to be competent unless proven otherwise, children and youth are "still too often presumed not to be competent, and their competence must be assessed in order to be recognized" (WHO, 2021, p. 7). Internationally, a plethora of legal frameworks exists for such a task: some countries set an age limit at which minors may make healthcare decisions; most countries do not and instead leave the task of assessing competence to healthcare providers.

Likewise, UN General Comment No. 12 and the UNCRC say that the assumption should be that a child is capable of expressing his or her own views, rather than incapable. The General Comment states that "it is not up to the child to first prove her or his capacity" (para. 20, emphasis added). The General Comment does not define capacity but does define maturity within the context of Article 12 as being "the capacity of a child to express her or his views on issues in a reasonable and independent manner," and "the ability to understand and assess the implications of a particular matter" (para. 30).

Other commentary suggests that the use of the term "capable" in Article 12 does not seem to mean "having capacity" to form a view (CBA, 2023; Mol, 2019). All that is required is a "formulation of a view, absent any understanding by the young person of how or why they formed the view, the basis of the view, or the consequences of voicing the view or acting on it" (CBA, 2023). Article 12 likewise reflects a view of capacity as evolving, as it provides that the child's views be given due weight in accordance with his or her age or maturity, suggesting greater weight is given as the child ages and becomes more mature, as this implies a greater degree of understanding on the part of the child and the nature and consequences of their articulated view (CBA, 2023; UN General Comment No. 12, paras. 20-21).

UN General Comment No. 20 on the Implementation of the Rights of the Child During Adolescence recommends that "States review or introduce legislation recognizing the right of adolescents to take increasing responsibility for decisions that affect their lives" (WHO, 2021, p. 7). It also provides that the right to give medical consent is distinct from "confidential medical counselling and advice, and should not be subject to any age

limit" (WHO, 2021, p. 7). Article 39 provides that adolescents may access counselling and advice without the consent of a parent or guardian, regardless of age (WHO, 2021). WHO says that "consideration should also be given to a legal presumption that adolescents are competent to seek and have access to preventative or time-sensitive sexual and reproductive health commodities and services" (WHO, 2021, p. 7).

It is important to stress the confidentiality of counselling services. Lack of confidentiality, whether perceived or actual, was a consistent concern expressed by many of the youth we engaged with through our research. As one young person shared:

> *"There were many things that I stated to my therapist that I thought were confidential, and the therapist would blab everything to my guardian. Professionals repeatedly act in the best interest of what the parents want."*

Photo by Ryan Tauss on Unsplash

Mature minor doctrine: "Gillick competence"

> *"My capacity to make healthcare decisions was quite strong. I had the intellectual ability and understanding. And also something I wanted to do for myself. I felt empowered to be in control of my healthcare decisions and what was happening to me. But in other areas of my life, maybe I wasn't as confident."*
>
> Youth Engagement

The mature minor doctrine addresses the capacity of children to make decisions for themselves—especially in medical matters—even when those decisions are contrary to their parents' positions. The doctrine arises from the House of Lords decision in *Gillick v. West Norfolk and Wisbech Area Health Authority and another* (1985).

In *Gillick*, the Department of Health and Social Security (DHSS) had issued guidance to doctors indicating that in certain cases a doctor could legally prescribe contraception for a girl under 16 years old without the consent of her guardian. Mrs. Gillick, who was the mother of 5 daughters, objected to this and instituted legal proceedings seeking a declaration from the Court that the guidance given by the DHSS was unlawful.

The Court declined to issue that declaration and instead ruled that a minor who is "capable of understanding what is proposed and of expressing his or her own wishes" should be found to have "the capacity to express them validly and effectively and to authorise the medical man to make the examination or give the treatment which he advises" (Gillick, 1985, p. 409).

In reaching that decision, the House of Lords explained that "...parental rights to control a child do not exist for the benefit of the parent. They exist for the benefit of the child" (Gillick, 1985 p. 410). In circumstances where a child reaches "sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decisions", a parent's right "yields to the child's right to make his own decisions" (Gillick, 1985 p. 422). The Court cautioned against the imposition of "fixed limits" on the process of growing up: "the price would be artificiality and a lack of realism in an area where the law must be sensitive to human development and social change" (Gillick, 1985 p. 421).

The *Gillick* case is "fundamental to the modern understanding of how law can include considerations of the capacities of children and has had a massive influence on efforts to establish what this may look like in practice. *Gillick* has also evolved to a standard for questions regarding children's capacity across various legal proceedings" (Henderson-Dekort et al., 2022, p. 5).

The test according to *Gillick* is, whether the child has "sufficient understanding and intelligence" to consent to the matter in question (1985, p. 422). However, the language of this test has led to confusion about the level of understanding children should have and in which contexts (Cave, 2014), and there is a lack of consistency regarding its application (Daly, 2020):

> The lack of clarity about what capacity entails can sometimes pose a problem. Disagreements can arise between patients and doctors about treatment, though this may not reach the public eye (Cave and Stavrinides, 2013:5). There can then be differences of opinions between professionals as to whether the child in question actually *has* capacity (p. 475).

It is important not to be overly strict in applying the Gillick or mature minor test. Daly (2020) argues,

> Applying the principle of non-discrimination when considering a child's capacity also means refraining from an overly conservative application of Gillick and other standards of assessment of capacity. Being 'fully' informed, as Gillick requires, is beyond the requirements for an adult, who simply needs to be aware in broad terms of the nature of the treatment (Rogers v. Whitaker [1992] 175 CLR 479, 489 see also S (Child as Parent - Adoption - Consent) [2017], para. 60). The court in *S v. SBH* advocates 'a shift away from a paternalistic approach in favour of an approach which gives significantly more weight to the autonomy of the child in the evaluation of whether they have sufficient understanding' (para. 63). Careful consideration should be given to a child's capacity in circumstances such as obtaining consent for medical treatment. Yet one should avoid an overly stringent interpretation of what a child's understanding entails (p. 485).

Informed consent laws

Each province or territory in Canada has its own legislation on healthcare decisions that differ to varying degrees from one another.

In British Columbia, the age of majority is 19 years, and there is no specified age of consent for medical treatment. According to the *Healthcare (Consent) and Care Facility (Admission) Act*, individuals who have reached 19 years of age are presumed to be capable unless proven otherwise. The *Infants Act* governs individuals under 19 years old, allowing them to consent to medical treatment—which is broadly defined as "anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other heath related purpose, and includes a course of health care" - if they demonstrate capacity (s.17 *Infants Act* (1996)). However, consent is deemed invalid unless healthcare providers have taken reasonable steps to ensure treatment aligns with the minor's best interests.

Section 17 of the *Infants Act* stipulates that a child's consent is "effective and it is not necessary to obtain a consent to the health care from the infant's parent or guardian" only if:

17(3)... the healthcare provider providing the healthcare

> a) has explained to the infant and has been satisfied that the infant understands the nature and consequences and the reasonably foreseeable benefits and risks of the healthcare and

(b) has made reasonable efforts to determine and has concluded that the healthcare is in the infant's best interests.

This determination of capacity is significant and relies on both legal standards and medical evaluations, and requires that healthcare providers appropriately assess the minor's capacity in order to ensure that the treatment is in their best interests.

For an overview and summary of Canada's provincial and territorial consent laws as they pertain to children and youth in the context of healthcare decisions, see Appendix 1 on page 34.

Informed Consent and its overlap with child welfare legislation

Across Canada, child protection laws allow provincial agencies to make treatment decisions for children when a parent's refusal threatens their health or life. This typically involves apprehending the child and obtaining a court order within a short time frame, with parents and sometimes the child entitled to notification and participation. However, the situation becomes complicated when a child is deemed a 'mature minor', otherwise capable of making their own treatment decisions.

In a pivotal case, the Supreme Court of Canada ruled that applying a best interests lens to the question of a young person's competence to refuse medical treatment was not a breach of the child's constitutional rights, as long as the child was given the opportunity to demonstrate their competence as part of the decision-making process (A.C. v. Manitoba (Director of Child and Family Services)). In this case, a 14-year-old refused a blood transfusion on religious grounds despite medical advice indicating there was an imminent, serious risk to her health and perhaps her life. Her parents supported her decision and refused to authorize a blood transfusion. The child was apprehended by the state.

Photo by Ana Klipper on Unsplash

The state argued that the relevant child welfare legislation allowed the court to authorize medical treatment that it considered to be in the best interests of the child if the child was under 16, without regard to the child's competence to otherwise consent to or refuse medical treatment. Justice Abella disagreed with such a strict reading of the legislation and instead found that "it is inherently arbitrary to deprive an adolescent under the age of 16 the opportunity to demonstrate sufficient maturity when he or she is under the care of the state" (para. 114). Any other interpretation of the legislation would likely be "...arbitrary and discriminatory. A rigid statutory distinction that completely ignored the actual decision-making capabilities of children under a certain age would fail to reflect the realities of childhood and child development" (para. 116).

In her decision, Justice Abella said:

> With our evolving understanding has come the recognition that the quality of decision-making about a child is enhanced by input from that child. The extent to which that input affects the "best interests" assessment is as variable as the child's circumstances, but one thing that can be said with certainty is that the input becomes increasingly determinative as the child matures. This is true not only when considering the child's best interests in the placement context but also when deciding whether to accede to a child's wishes in medical treatment situations (para. 92).

This 'sliding scale' approach, where the degree of deference to the child's decision increases with maturity, aligns with Article 12 of the UNCRC, which underscores the importance of considering children's views according to their age and maturity.

Cave (2014) argues that in its decision in *A.C. V Manitoba (Director of Child and Family Services)*, the Supreme Court of Canada moved closer to the view that "though the minors' views may not be authoritative, they are always relevant, because Article 12 of the UNCRC demands that all children are consulted about decisions made about them" (p. 116).

Case law

Subsequent cases have followed this approach in recognizing the importance of determining the proper balance between the child's views and the risks to the child.

In Alberta (*Child, Youth and Family Enhancement Act*, *Director) v. K.R.*, (2010) the Supreme Court of Canada held that decision-makers should use a "functional" approach when assessing a child's capacity to make decisions about their healthcare. This means that the focus should be on the child's ability to understand the relevant information and appreciate the consequences of their decision, rather than on their age or cognitive abilities.

In *C.C. v. Children's Aid Society of the Region of Peel,* (2012), the Ontario Superior Court of Justice held that children have the right to make their own healthcare decisions if they are capable of doing so. The Court emphasized that decision-makers should

take into account the child's wishes and opinions, and should only override the child's decision if it is necessary to protect their health or safety.

Assessment models

> *"It is so frustrating to realize that if I had known, I would have never went on it. It is so frustrating to me that no one explained it to me. When you are in the doctor's office, someone is always talking over you. The doctor does not listen. Doctors and parents go to medications as a solution when in reality the medications are the problems or at least exacerbated it. If I had not been drugged out of my mind, I would have been better."*
>
> Youth Engagement

Healthcare providers often do not have sufficient time in a patient appointment to fully assess a young person's capacity. This is notwithstanding the fact that the proper assessment of a child's capacity is critically important. If a child or youth is assessed as lacking capacity when this is not in fact the case, that child or youth "lose[s] control over [their] life"; by corollary, if a child or youth is assessed as having capacity when they do not, then they "could suffer harms and injuries and[...]would be told that that was [their] choice" (Herring, 2016, as cited in Daly, 2020, p. 473).

The following three assessment models are examples primarily used by healthcare providers to assess the competence or capacity of a child or youth to make their own decisions in healthcare. They are described here in summary, with more details provided in Appendix 2 on page 37.

MacArthur Competence Assessment Tool

The MacArthur Competence Assessment Tool (MacCAT) is a structured set of interview instruments developed by Grisso and Appelbaum in 1998 (Hein et al., 2015). The instrument focuses on assessing four areas of the patients' understanding, including information about their condition and recommended treatment, risks, benefits, nature of the situation, and the ability to express a choice.

Multidisciplinary-developed assessment model

This four-step assessment model developed by Michaud and others (2015) involves assessing the patient's understanding of their situation; evaluating their reasoning and application of logic; assessing their thinking regarding different options; and ensuring they are able to express a choice.

WHO 4-step assessment model

WHO provides another four-step assessment model involving joint exploration of the situation and options; coming to a common synthesis of the situation; deciding whether the patient has capacity to make an autonomous decision in the particular situation and given time; and providing a follow-up regardless of outcome.

Capacity to make healthcare decisions: specific considerations

Medical assistance in dying (MAID) for children and youth

In Canada, the regulations for medical assistance in dying (MAID) stipulate that applicants must be 18 years or older. Notwithstanding this, certain regions in Canada grant mature minors the authority to make significant decisions about their healthcare, including the ability to consent to or refuse life-saving medical interventions. Dying With Dignity Canada (DWDC) advocates for extending this autonomy within MAID, emphasizing the importance of robust eligibility criteria and safeguards to protect vulnerable individuals. DWDC (2021) proposes revising the current age requirement to include individuals "at least 12 years of age and capable of making decisions about their health" (para. 5), prioritizing capacity and maturity over strict age limits.

DWDC (2021) suggests that,

> Mature minors who might be seeking to access MAID in Canada would likely be very similar to the adults who seek to access MAID: individuals with a grievous and irremediable Medical condition who are facing significant suffering (para. 14).
>
> and
>
> Overall, a mature minor who might want to access MAID would likely be one who has been engaged in their healthcare over a sustained period, who expresses a deep understanding of the consequences of their decisions, who faces a condition that is irreversibly progressing, and who has spiritual, physical, psychological, and/or existential interests in contributing to a decision about their death and/or accessing an assisted death at the end of their life. Like all individuals accessing MAID, these decisions would not be easy, so it would be reasonable to presume that mature minors making these decisions would have a close social circle who were able to provide the person with support in making this important decision (para. 15).

DWDC emphasizes the need for informed consent from competent parents or guardians for minors aged 12 to 15 seeking access to MAID. For minors aged 16 and 17, DWDC suggests additional consultations between assessors and parents or guardians. It is essential to understand that the concept of a 'mature minor' varies and exists on a spectrum rather than a binary classification, encompassing different levels of decision-making capability across various contexts and over time. The precedent set by the *A.C.*

v Manitoba decision highlights that mature minors may possess legal capacity to make end-of-life decisions, depending on their understanding and ability to consent. Bill C-7, which received Royal Assent and underwent Parliamentary Review in 2023, brings significant changes to MAID, including provisions for mature minors and individuals with mental illness, as well as advance requests for MAID. Bill C-62 delays the expansion of MAID for three years from the current date, postponing broader access to MAID.

Transgender children and youth; the *Family Law Act* and *Infants Act*

> *"I'm transgender and when I was in the process of getting assessed for gender dysphoria, it was one of the few times where I feel like I was actually listened to. I shared my feelings, thoughts, and experiences, and my doctor wrote a report that reflected that he was really listening and thinking about what I told him. Because he took me seriously, I was able to get the help I needed as quickly as possible. This genuinely saved my life. I was very suicidal and wouldn't have gone much longer without help fast. He listened to what I wanted and was able to help me get it."*
>
> Youth Engagement

When speaking about the legal rights of transgender children and youth seeking medical care, barbara findlay, KC (2022), is unequivocal: "BC law regarding transgender youth consent to gender-affirming medical treatment is unambiguous: the youth has the exclusive right—provided certain conditions are met by their healthcare provider" (p. 65).

An important decision in this area is the case of *AB v CD* (2020), involving a transgender 13-year-old, assigned female at birth, who sought gender-affirming medical treatment. His doctor recommended puberty-delaying hormone therapy, which his father contested. The youth brought an application to court seeking a declaration that he was entitled to make his own medical decisions and that the treatment he sought was in his best interests. The father sought an injunction to prevent treatment.

The lower court dismissed the father's application for an injunction and held that his guardianship right to determine his child's medical care was limited by section 41(f) of the *Family Law Act* (2011), which is subject to section 14 of the *Infants Act*. Section 17 of the *Infants Act* provides that if a minor comprehends a proposed treatment and its implications, and if the medical provider determines the minor to be competent and the treatment to be in their best interest, then the minor holds the exclusive right to consent to the treatment. Accordingly, the court ruled that AB had the sole authority to consent, and his father could not intervene. This decision was upheld by the BC Court of Appeal.

The BC Court of Appeal outlined the duties of healthcare professionals when dealing with patients under 19 years old. It clarified how the *Infants Act* and *Family Law Act* apply in scenarios where there is disagreement between youth and parents regarding medical treatment. The court affirmed that healthcare providers, rather than parents,

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are responsible for assessing the capacity of minor patients to consent to treatment and determining the issue of whether the treatment is in the patient's best interest. If a healthcare provider deems a young person capable and concludes that the treatment is in their best interest, the youth alone has the authority to consent to or refuse treatment. Providers must adhere to the standards set by their professional bodies and human rights tribunals when providing healthcare to minors.

Subsequent cases have similarly allowed mature transgender minors to make their own decisions respecting gender affirming surgery.

In *A.M. v. Dr. F* (2021) a parent obtained an order to prevent a doctor from providing gender reassignment surgery for their child without advising the other parties that they were doing so. The court later set aside that order and dismissed the proceeding, with the court granting a subsequent order preventing the parent from relitigating.

And in *G.M.S. v. Dr. Z* (2021) a parent sought an injunction to prevent their gender dysphoric child from getting a gender affirming mastectomy. The court denied the injunction noting that the child was "mature enough to make his own medical decisions regarding gender affirming medical procedures" (para. 12). Citing these cases, barbara findlay, KC, concludes that "in BC, the law about consent to treatment by transgender youth is unambiguous" (2022, p. 66).

Disclosure of children's personal health information

Privacy legislation governs the collection, use and disclosure of personal health information in BC, including the personal health information of a minor.

The Personal Information Protection Act, SBC 2003, Ch.63 ("PIPA") regulates private sector organizations, businesses and not-for-profit organizations in the collection and use of the personal information of individuals while allowing an individual to access their personal information.

In the healthcare sector, the legislation protects personal information that is held by a private health care provider working in the community. Similarly, the Freedom of Information and Protection of Privacy Act , [RSBC 1996] Ch. 165 ("FOIPPA") "applies to health authorities, hospitals, and urgent care clinics, and to providers working within them" (Doctors of BC, n.d.).

Because many doctors work both in private clinics and in hospitals, their records may be covered by both pieces of legislation. Regardless of which Act applies, medical professionals are responsible to protect any personal information that they might have about a young person and to disclose it only in accordance with the legislation.

Both Acts allow an individual to request personal information, including personal health care information from their health care providers, and to control access to their personal health care information.

Can a guardian override a minor's consent to release of medical information?

When a minor is incapable of exercising their right to control access to their medical information, the Regulations allow a guardian who has the necessary guardianship powers to control those records, including requesting copies of medical records (PIPA Regulation 473/2003 s.2(2); FOIPPA Regulation155/2012 s.3(1) and (2)).

Determinations of whether a minor is "incapable" fall to the medical provider. Before a healthcare provider can release any information about that child to their guardian or adult representatives, they must conclude that a child is "incapable". The fact that the person seeking the information is a guardian is irrelevant unless the child is first found to be incapable.

In a case before the British Columbia Information and Privacy Commissioner, the father of a child made a request for personal information about their minor son under the Personal Information Protection Act (PIPA) to the Richmond City Baseball Association. The Association refused to disclose the information and the guardian sought a ruling from the Privacy Commissioner that would require the Association to provide that information to the guardian. The adjudicator ruled that a guardian would only be able to access his minor son's personal information under PIPA if all three of the following conditions were met:

1. The applicant is the son's guardian,
2. The son is a minor; and
3. The son is incapable of exercising his own access rights.

As there was no evidence that the young person was not capable of exercising his own access rights, the adjudicator declined to allow the parent's application. (Order P22-04; Richmond City Baseball Assn. (Re) [2022] B.C.I.P.C.D. No. 42, para 6-9).

The same legal test applies to requests for medical information about a minor, and a capable minor has the right to deny their parent access to their information, even if the parent is a legal guardian of the minor.

These Acts reinforce the importance of respecting the capacity of a mature minor to make decisions about their own healthcare and to control their personal information.

Consequences of forced treatment

> *"I was being medically abused. I was not given the opportunity to make any decisions about my medical care. There were cases when I if I was able to make decisions I would have made different choices. When I was 12, I was treated for scoliosis, and put in a full body brace. I was only given 15 minutes to think it over, if I was given all of the information, I would have made a different choice."*
>
> Youth Engagement

In situations where a child or youth's healthcare decision is not respected, or otherwise substituted for that of an adult, such as a parent, guardian, or healthcare provider, literature suggests that outcomes may be deleterious to that child or youth (Alderson & Goodwin, 1993). This is particularly the case in situations involving severe or prolonged treatment, a conclusion that is echoed by SCY's engagement with children and youth (see page 32).

Alderson and Goodwin (1993) explain, "The literature and law on consent to children's treatment tend to assume that almost any life-extending treatment is better than none, and that refusal of proposed medical treatment is inevitably incompetent, though the suffering this causes has been critically documented" (p. 5).

Specifically, in the case of severe or prolonged treatment, Alderson and Goodwin's (1993) review of the literature found that such treatment "can induce terror and despair in the child" (p. 4), and that this experience of terror can be tantamount to the reactions of torture victims:

> Children who perceive treatment as worse than the disease risk having similar reactions to those of torture victims. Torture is defined as `breaking down a person's sense of identity'. It is exacerbated when people are in a strange culture, such as a hospital ward. It arouses feelings of utter helplessness, being out of control of events and one's own body, inability to sleep, or concentrate, irritability, confusion between feeling bad and being bad, the disintegration of mind and body. `A perfect way to cope with torture and prison is to disassociate your feelings from your experience[...] If it becomes a habit, children become emotionally crippled (p. 4).

In the case of life-saving treatment, Alderson and Goodwin note: "It is very rare for children to refuse life-saving treatment, and[...]their response should then be taken very seriously. Such refusal can be deeply perturbing with competent adult patients yet is respected in law. Why should not informed, wise children receive the same respect in cases when health professionals are uncertain what is the correct choice?" (1993, p. 7).

D. Conclusion and Summary of Key Findings

Legislation may be complex, but the importance of upholding children's participatory rights in healthcare contexts is simple. Growing evidence from academic literature, legal analysis, and youth engagement all point to the positive benefits for young people to be heard and taken seriously when decisions are made about their healthcare. Throughout the course of research conducted, the following key findings emerged:

1. Regardless of their decision-making abilities, all children and youth have a right to be heard and to express their views in decisions concerning their healthcare.

2. As in adults, capacity of children and youth encompasses a variety of factors and develops at different rates. It is an evolving trait that may be more or less present in different contexts and can be assessed through a variety of models available to healthcare providers.

3. Healthcare must be patient-centred, with the views and interests of the young patient meaningfully considered in the provision of services. The onus must be on the healthcare provider to find an effective strategy to communicate and connect with their child or youth patient.

4. Dismissal and invalidation by healthcare providers, parents, and other adults contributes to significant negative impacts on children and youth including reduced self-esteem and confidence in their treatment plans.

5. Children and youth would greatly benefit from neutral, third-party support in medical settings that focuses only on their interests, needs, and views.

6. For many children and youth, making healthcare decisions can be an empowering experience, helping them develop individual agency.

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Youth Engagement Methodology & Data

The Child Capacity Research Project sought to embed key values and principles in the research process that in turn shaped the research methodology, community engagement, and analysis of the results. These values and principles pertained to striving for accessibility, highlighting intersectionality, valuing lived and living experiences, and others crucial for meaningful engagement and research.

It was this approach, as well as the calls to action from participants, that allowed for the recognition that while the project was intended to look at four key topics with complex systems of their own, they are also interconnected in many ways. In addition, it was noted throughout the youth engagement that it was sometimes difficult for participants to speak to one system without describing the impact of another. Thus, we advise readers to recognize the intersectionality of the lived experiences reflected in the information below and that also has contributed to the richness of qualitative data that emerged.

ENGAGEMENT METHODS:

Three distinct engagement methods were utilized to provide accessible opportunities for contribution from youth and young people, primarily below the age of 30, with lived and living experiences in relation to the research topics. All three options were offered to every participant prior to written consent being provided:

Survey:

- An anonymous, online survey consisting of 3 questions was made available during the entire duration of the project
- The nature and structure of the questions allowed for participants to respond based on the experience they deemed relevant to contribute

Interviews:

- 1-hour virtual Zoom sessions with a participant and two members of the CCRP team
- Discussion questions* were provided in advance
- Follow-up interview opportunity offered

Listening Circles:

- 1-1.5 hour virtual Zoom sessions with existing youth advisories, councils, and other programming groups
- Sessions were coordinated in collaboration with group/organization leads, coordinators, and/or supporting staff
- Discussion questions* were provided in advance
- Follow-up session and/or interview with interested participants offered

***Note:** The following three questions were used in all methods of engagement and were specified (in Listening Circles and interviews) based on the topic participants wished to address. However, it is crucial to note that while these were the primary questions asked, discussions often built on what was shared in the session. The evolving conversations differed per group / participant, and as a result, the extent of questions that organically emerged were not able to be included in the list below.

Discussion Questions:

1) How do you define "capacity"? Based on your understanding, do you feel you have had capacity to make decisions, or the opportunity to use your capacity to participate in decisions?

2) Can you tell us about a time [in a family law / mental health / healthcare decision / child protection matter] when you felt like your opinion was valued and taken into consideration?

3) Based on your experience [in a family law / mental health/ healthcare decision / child protection matter], how do you think things could be improved so that your capacity to make decisions and be heard is better respected?

Stakeholders & Subject Matter Experts:

- Stakeholders and subject matter experts across sectors were invited to provide feedback on the draft outlines for all four research papers at a virtual roundtable held during the earlier stages of the project
- Individuals part of community networks were also selectively invited to provide feedback on research paper drafts as they were developed by topic

Outcomes:

- 78 participants across all methods of the youth engagement contributed their feedback by sharing their lived and living experiences
- An analysis of themes from the youth engagement by topic can be found below

Note: While the project sought to uplift intersectional experiences of young people across all four topics, there are limitations to those reflected in this paper. It is recommended that future research initiatives dedicate efforts to highlight the specificities of identities of young people that may uniquely inform the nature of their experiences with respect to the four topics examined in this project (e.g. gender and sexuality).

THEME CODE	THEME:	DETAILS/VARIANCES
1	Limited understanding of Intersections of identity	• Medical practitioners unable to a**cknowledge complexities of situation specific to racial identity** • Need for **elimination of ageist-based dismissal** of young people's experiences
2	Power dynamics of decision-making	• Designated professionals with credentials **defaulted to over needs and interests of young people**
3	Self-advocacy	• Young people **feeling need to represent their own interests** on a long-term basis (i.e. long journey of self-advocacy) • **Greater autonomy** for young people **co-related with becoming older** • Need for young people to **be trusted to be able to decide their own need for care/treatment** • **Young people may 'give up' on getting support** (e.g. diagnosed) for conditions they have due to being repetitively dismissed and invalidated
4	Lack of proper practice	• **Poor transition planning and care** • **Lack of effective and coordinated communication** among medical practitioners • Consequence **of onus shifting to young people to determine course of action** • **Detrimental health and financial impacts** resulting from not being informed (e.g. going 'cold turkey' due to cost of expensive medication) • **Variance in experiences of assessment** practices at different institutions
5	Need for due diligence	• Medical practitioners noted to be **operating on assumptions** • Practitioners noted to **need more education and training** in providing care/service to young people and challenges they navigate • **Desire for medical practitioners/staff that have lived and/or living experiences** with the same mental health issues as patients being serviced

6	Need to demonstrate genuine care	• Medical practitioners **need to make efforts for active listening, consulting, and demonstrating belief** in young people's experiences • Young people may not disclose information due to **not being believed** • Meaningfully **listening to youth** noted to be reason that **immediate and life-saving treatment was made available** • Need to support young people to **express themselves**
7	Shifting priority from 'fixing' patients	• Need to **situate intervention in larger context** as opposed to fixating on what is 'wrong' with patient
8	Lack of meaningful consultation	• **Dialogue only existing between guardian/family and medical practitioners** • Young people's requests **being "heard" but not incorporated** into decisions • **Opportunity to express choice/preference not provided** even when multiple **options available**
9	Contradictory practice of 'best interests'	• **Lack of any 'interests' of the child** in practice of 'best interest'
10	Improving effective delivery of service	• **More funding** to allow greater availability of support and resources • **Need support from systems/practitioners in advocating for services** (e.g. gender affirming care for young people who are Trans*) • **Need to shift pace of service delivery** (i.e. young people not having to wait for extended periods of time)

Appendix 1:
Overview of Canadian laws on age of consent

PROVINCE/TERRITORY	LEGISLATION DETAILS
British Columbia	The age of majority is 19 years old. No specific age of consent for treatment is mentioned. The *Healthcare (Consent) and Care Facility (Admission) Act* presumes adults (19 years or older) to be capable unless proven otherwise. The *Infants Act* applies to those under 19 years old, allowing consent if capacity is demonstrated. Consent must also align with the minor's best interests.
	Healthcare (Consent) and Care Facility (Admission) Act, RSBC 1996, c 181
	Infants Act, RSBC 1996, c 223
Alberta	The age of majority is 18 years old. No specific age of consent for treatment is mentioned. Patients under 18 years old are presumed without capacity but can be assessed as 'mature minors' capable of consenting to treatment.
	Personal Directives Act, RSA 2000, c P-6
	Alberta Health Services, 'Consent to Treatment/Procedures Minor/Mature Minors' (PRR-01-03)
Saskatchewan	The age of majority is 18 years old. No specific age of consent for treatment is mentioned. Minors under 18 years old can consent to treatment if deemed capable ('mature minors').
	Healthcare Directives and Substitute Healthcare Decision Makers Act, 2015, SS 2015, c H – 0.0002
	Saskatoon Health Region 'Consent, Informed Consent' (Policy 7311050-002)
Manitoba	The age of majority is 18 years old. No specific age of consent for treatment is mentioned. Those 16 years or older are presumed to have capacity for healthcare decisions, while those under 16 years old are presumed not to unless proven otherwise.

	Healthcare Directives Act, CCSM, c H27
	Substitute Consent to Healthcare, Report #110 (2004) Law Reform Commission
Ontario	The age of majority is 18 years old. No specific age of consent for treatment is mentioned. The Healthcare Consent Act presumes all individuals capable of understanding treatment information. The Substitute Decisions Act presumes individuals 16 years or older capable of giving consent unless proven otherwise.
	Healthcare Consent Act, 1996 c.2
Quebec	The age of majority is 18 years old. Minors under 14 years old require parental or 'tutor' consent for treatment. Those 14 years or older can consent to necessary care. Court authorization is necessary for certain cases.
	Quebec Civil Code, Articles 14–18
	Act Respecting End-of-Life Care RSQ c S-32.0001
New Brunswick	The age of majority is 19 years old. No specific age of consent for treatment is mentioned. Minors 16 years old can consent to medical treatment like adults. Those younger than 16 years old can consent if capable and in their best interests.
	Medical Consent of Minors Act, SN.B 1976, c M-6.1
Nova Scotia	The age of majority is 19 years old. No specific age of consent for treatment is mentioned. Those with capacity can consent to treatment.
	Personal Directives Act, SNS 2008, c 8
Prince Edward Island	The age of majority is 18 years old. No specific age of consent for treatment is mentioned. Those capable may consent to treatment.
	Consent to Treatment and Healthcare Directives Act, RSPEI 1988,c C-17.2

Newfoundland & Labrador	The age of majority is 19 years old. No specific age of consent for treatment is mentioned. Those 16 years or older are presumed competent to make healthcare decisions.
	Advanced Healthcare Directives Act, SNL 1995, c A-4.1
Yukon	The age of majority is 19 years old. No specific age of consent for treatment is mentioned. Those capable may consent to care.
	Care Consent Act, SY 2003, c 21
Northwest Territories	The age of majority is 19 years old. No specific age of consent for treatment is mentioned. Adults can consent to treatment.
	Personal Directives Act, SNWT 2005,c16
Nunavut	The age of majority is 19 years old. No specific age of consent for treatment is mentioned. Adults are presumed capable unless proven otherwise.
	Guardianship and Trusteeship Act, SNWT (Nu) 1994, c 29

Appendix 2: Assessment Tools

The MacArthur Competence Assessment Tool (MacCAT)

The MacArthur Competence Assessment Tool (MacCAT) refers to a set of structured interview instruments. The MacCat-Treatment (MacCAT-T) instrument is used to evaluate competence in healthcare decision-making and was developed by Grisso and Appelbaum in 1998 (Hein et al., 2015).

As described by Henderson-Dekort and others (2022), "[t]his instrument aims to assess patients' capacity to make decisions surrounding treatment by assessing four areas of the patients' understanding:

(1) Information about their condition and recommended treatment;
(2) The potential risks and benefits of treatment options;
(3) The nature of their situation and consequences; and
(4) Their ability to express a choice" (p. 13, citing Grisso et al., 1997).

Many have adapted the MacCAT-T to assess a minor's competence (Michaud et al., 2015; Hein et al., 2015), as the instrument "employs both quantitative and qualitative elements to gather insight into a patient's capacity to make medical decisions" (Henderson-Dekort et al., 2022, p. 13).

Multidisciplinary-developed assessment model

The second model is offered by Michaud and others (2015). The framework advanced by this group of scholars arose out of a two-day summit of international healthcare professionals, psychologists, ethicists, and legal scholars, inter alia, for the purposes of providing policy guidance on assessing the capacity of minor adolescents for autonomous decision-making without a third party authorization.

According to Michaud and others (2015), the assessment of adolescent decision-making capacity includes the following six components:

(1) Reviewing the legal context in accordance with the principles enshrined in the UNCRC;
(2) Establishing an "empathetic relationship" between the adolescent and the healthcare professional or team;
(3) Respecting the adolescent's development stage and capacities;
(4) Including "relatives, peers, teachers, or social and mental health providers" with the adolescent's consent, if appropriate or relevant;
(5) Controlling for "coercion and other social forces" that may influence decision-making; and
(6) Utilizing a "deliberative stepwise appraisal" of the adolescent's decision-making process (p. 361).

In terms of the final component, a "deliberative stepwise appraisal" or approach involves "understanding the different facets of the given situation, reasoning on the involved issues, appreciating the outcomes linked with the decision(s), and expressing a choice" (Michaud et al., 2015, p. 361).

The specific approach devised by this group is informed by the above components and the MacCAT-T instrument, creating a four-step assessment model (Michaud et al., 2015, p. 364). The four steps are thus:

(1) "Assess the adolescent's understanding of the different facets of the situation".

a) Information about the disease or condition and recommended treatment should be comprehensive and provided by the healthcare provider in simple, accessible language (Michaud et al., 2015, p. 364). The adolescent should be asked to interpret what they have understood, speaking to the nature and prognosis of the condition, and the availability of treatment options (Michaud et al., 2015). The healthcare provider should specifically address the short- and long-term consequences of different treatment options.

(2) "Evaluate the adolescent's reasoning about [their] present situation, health condition, and therapeutic options".

a) The assessor should explore how the "young patient applies logic to clarify information, verifies facts, and justifies change or persistence in opinions and beliefs based on newly acquired or existing information" (Michaud et al., 2015, p. 364). These facets can be explored through asking questions, such as "What do you understand of the consequence of stopping treatment in your situation", or "What does it mean for you if you do not take any medication"? During this stage, it is appropriate to "explore how the adolescent feels about his parents' or relatives' views and preferences and how these opinions would impact on [their] choice" (Michaud et al., 2015, p. 364)

(3) "Assess the adolescent's thinking on various options".

a) It is important that an assessor "be very careful in accompanying the adolescent in the progression of [their] understanding of the situation" in light of the "specific difficulty of young adolescents[...]to foresee the long-term consequences of any choice, as the capacity to reason in an abstract and long-term perspective may be hampered because of neurodevelopmental limitations" (Michaud et al., 2015, p. 364). Questions that may assist in achieving this end are, "Can you explain why you prefer this option to another?", "Can you compare these two options and list the risks and benefits for each?". Michaud et al note that unless the situation at hand is urgent, the assessment should occur over a minimum of two separate occasions, and that healthcare providers should reassess the adolescent's understanding and reasoning capacities on multiple occasions (2015).

(4) Ensure that "the adolescent is able to express a choice".

a) After the above three steps, the assessor should then ask the adolescent to express their preferred choice and provide justifications for their decision.

> If the assessor is of the opinion that the adolescent has not understood the potential consequences and does not display an appropriate level of reasoning, then they may not be granted full competence and the healthcare provider may decide that the parents or another guardian should be involved in decision-making. There are also circumstances where an adolescent may themselves feel unable to make a decision and, consequently, may not be granted full competence.

WHO 4-step assessment model

WHO provides an additional four-step assessment model for assessing and supporting adolescent capacity (2021, p. 8).

(1) "Joint exploration of the situation and options"
a) The assessor or healthcare provider (these are often the same) should explore the important elements of decision-making and the overall situation. This should include "the adolescent's psychosocial life, risks, and resources" (WHO, 2021, p. 8). The healthcare professional's role at this stage is to "provide all the necessary information in appropriate language on the framework of care, the medical condition, and the options to help the adolescent in making a choice" (WHO, 2021, p. 8).

(2) "Common synthesis of the situation"
a) This stage involves the assessor summarizing the issues that arose in the first step to "ensure common understanding" (WHO, 2021, p. 8). In this analysis, the healthcare provider should "be particularly attentive to elements that are likely to alter a decision and address them as appropriate to allow deliberation with the adolescent and any relevant partners in order to reach a consensual decision" (WHO, 2021, p. 8). This may involve parents, legal guardians, or other relevant people.

(3) "Decision point"
a) At this stage, the healthcare provider or assessor decides whether the adolescent has the capacity to make an autonomous decision in a given situation at a given time.

(4) "Follow-up"
a) The healthcare provider should outline guidelines for follow-up, "whether or not consensus is reached on a decision" (WHO, 2021, p. 8).

WHO notes that these four steps are not designed as a "rigidly linear process", but instead should be used as an "integrated, dynamic approach" (WHO, 2021, p. 9). Less complex situations may not require all four steps, while more complex cases may require thorough scrutiny at each stage:

> Decisions, especially complex decisions, cannot be made without exploration of the adolescent's overall and psychosocial situation. They may be vulnerable in a number of ways that could either alter their decision-making capacity or threaten their healthy development if they make a particular decision. It is also essential to identify the resources that can help the adolescent in making decisions. (WHO, 2021, p. 9)