

BEYOND CONSENT: SELF-DETERMINATION AND PROTECTING HIGH-RISK PATIENTS IN HEALTH CARE

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LILLA GARAYOVA

Pan-European University, Faculty of Law, Bratislava, Slovakia
lilla.garayova@paneurouni.com

CORRESPONDING AUTHOR

lilla.garayova@paneurouni.com

Abstract Modern healthcare is built on the principle of informed consent which is the basis of patient autonomy and self-determination. However, this model has its very clear limits when applied to high-risk and vulnerable patients whose decision-making capacity is impaired. This study examines what lies behind consent in healthcare and asks how legal systems can protect high-risk patients without undermining their dignity, agency and human rights. The analysis adopts a comparative legal approach. It relies on international instruments and national examples from diverse legal traditions. The article argues that vulnerability should not serve as a justification for paternalism or uncontrolled coercion. Going beyond consent does not mean abandoning autonomy, it means reconceptualizing it in a way that ensures self-determination and protection for those most vulnerable in health care systems.

Keywords

informed consent,
patient autonomy,
vulnerability,
supported decision-
making,
human rights in health
care

1 Introduction

Imagine a patient who fails to fully understand their medical options - an elderly man with advanced dementia who refuses necessary surgery, or a teenager trapped in addiction who insists he does not need treatment. Modern healthcare is based on informed consent, the idea that patients have the right to decide about their treatment. But what happens when patients are high-risk and vulnerable, unable to protect their own interests or make informed decisions? “Beyond consent” means finding a way to support patient self-determination while simultaneously protecting vulnerable patients who lack full decision-making capacity. This study explores this balance, rooted in international human rights law but illustrated with real-world examples. We will examine how law and ethics address patients with cognitive impairments, psychiatric illnesses, addictions, and other high-risk situations, and propose innovative approaches to protect their well-being without sacrificing their dignity and autonomy. Methodologically, this article uses a doctrinal and comparative legal analysis. The study primarily relies on binding international human rights instruments (the United Nations Convention on the Rights of Persons with Disabilities¹ (CRPD), the European Convention on Human Rights and Biomedicine² (the Oviedo Convention), the Convention on the Rights of the Child³ (CRC), and the UNESCO, Universal Declaration on Bioethics and Human Rights⁴ (UNESCO Declaration on Bioethics) and their authoritative interpretive bodies, complemented by the jurisprudence of the European Court of Human Rights (ECtHR) and selected national courts. Regarding national examples, the jurisdictions were chosen to showcase differences between legal traditions and regions. The selection is not intended as an exhaustive comparative survey but rather aims to demonstrate the range of approaches that States have adopted in balancing patient autonomy with protective measures for vulnerable populations.

¹ Convention on the Rights of Persons with Disabilities, adopted on 13 December 2006 by the United Nations General Assembly, UN Doc. A/RES/61/106, entered into force on 3 May 2008.

² Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, opened for signature on 4 April 1997 in Oviedo, ETS No. 164.

³ Convention on the Rights of the Child, adopted on 20 November 1989 by the United Nations General Assembly, UN Doc. A/RES/44/25, entered into force on 2 September 1990.

⁴ UNESCO, Universal Declaration on Bioethics and Human Rights, adopted on 19 October 2005 by the General Conference of UNESCO at its 33rd session.

Respect for patient autonomy – the right of an individual to make decisions about their own body and health – is a fundamental principle of modern medicine. Legally, this is enshrined in the requirement of free and informed consent for any medical intervention. For example, the Oviedo Convention explicitly states that “*an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.*” This means that treating a patient without their consent generally violates the person’s right to bodily integrity and autonomy. The EU Charter of Fundamental Rights similarly derives the patient’s right to informed consent from the right to personal integrity.⁵ In essence, informed consent is a practical expression of self-determination in healthcare: patients have the right to choose (or refuse) a treatment after being given clear information about the risks and benefits (Kraljić, 2010, p. 187–199).

This model of patient self-determination emerged as a response to the historical paternalism of medicine, where doctors once made unilateral decisions on behalf of patients. Today, almost all national laws have a provision that states that patients must participate in decisions about their health and voluntarily consent to treatment. Intervention without consent is usually considered a violation of rights, unless justified by exceptional circumstances. Providing treatment without the patient’s consent would be a violation of their bodily integrity and personal identity. The primacy of consent is also reflected in global bioethics: The UNESCO Universal Declaration on Bioethics affirms that medical interventions require prior, free and informed consent and that special protection must be provided for those who cannot consent.

The ideal of complete autonomy, however, has its limits. In actual clinical practice, not all patients are always fully autonomous. Some individuals lack the mental capacity to understand complex medical information or to foresee the consequences of their decisions. Others may be under the pressure of internal compulsions (for example, in the case of severe addiction) or may be minors and therefore dependent on others for decision-making. In these cases, health professionals face a tension between respecting the patient’s expressed wishes and preventing serious harm. The following sections consider who these high-risk or vulnerable patients are and how

⁵ Charter of Fundamental Rights of the European Union, proclaimed on 7 December 2000 in Nice and adapted on 12 December 2007 in Strasbourg, OJ C 326, 26 October 2012.

law and ethics have evolved to protect them beyond simple consent.

2 High-Risk Patients and the Limits of Consent

High-risk patients refer to individuals who are particularly vulnerable when making decisions about their own medical care. This vulnerability may arise from age (for example, young children or the elderly), cognitive or intellectual limitations, mental illness, or conditions such as severe substance abuse that can impair judgment. These patients are high-risk either because they are unable to protect their own interests or because they may be vulnerable to rights violations if additional safeguards are not in place. Simply obtaining consent (or refusal) from such patients may not be sufficient to ensure their well-being or respect for their true wishes. In some cases, they may lack the capacity to give valid consent; in other cases, they may consent or refuse in a way that endangers their health due to impaired judgment.

Legal capacity – the ability to understand and make decisions – is a key issue here. Under traditional law, adults are presumed to have the capacity to consent to or refuse treatment. However, if evidence shows that a person is unable to understand information or make a sound decision, they may be deemed incompetent to make that decision. Classic examples are an unconscious patient in an emergency situation (temporarily unable to consent) or a person with advanced dementia (perhaps permanently unable to fully understand). In such situations, requiring strict consent could paradoxically leave the person without protection (for example, treatment for a life-threatening condition would not be provided because the patient cannot consent). Therefore, every society has developed mechanisms that go beyond consent in these cases – from surrogate decision-making and guardianship to involuntary treatment laws – to protect those who are unable to make adequate decisions for themselves.

However, these safeguards must be balanced against the person's right to self-determination. The risk is that vulnerability can become a gateway to paternalism or even abuse. International standards stress that vulnerability should not mean a complete loss of autonomy. For example, the UN Principles for the Protection of Persons with Mental Illness (adopted by the UN General Assembly in 1991) state that even if someone has a mental illness, any treatment must be tailored to preserve

personal autonomy as much as possible.⁶ Treatment should be provided in the least restrictive environment and with the least invasive means necessary. These principles reflect the rule that interventions beyond consent are permitted only as a last resort and with strict safeguards, always with the best interests and rights of the patient in mind.

So, who falls into these high-risk patient categories? We will focus on a few main groups:

1. Patients with cognitive impairments (such as intellectual disabilities or diseases such as Alzheimer's disease), who may not fully understand medical information.
2. Patients with psychiatric disorders, who may have impaired judgment during acute episodes or pose a danger to themselves.
3. Patients with substance use disorders, whose compulsions may override rational health decision-making.
4. Children and adolescents, who are legally dependent on adult decisions and whose capacity to understand develops with age.
5. Elderly patients, who often face a combination of physical frailty, potential cognitive decline, and social dependence, making them vulnerable to the decisions of others.

Each of these groups faces different challenges regarding autonomy and protection. In the following sections, we will address each of these, examining how law and practice seek to go beyond consent – and how international human rights law should guide these efforts.

2.1 Patients with Cognitive Impairments

Patients with cognitive impairments include people with intellectual and developmental disabilities, as well as those with conditions such as dementia or brain injuries that affect their ability to understand. These patients may not fully understand complex medical information or the consequences of their decisions,

⁶ United Nations General Assembly, Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, adopted on 17 December 1991, UN Doc. A/RES/46/119.

complicating the standard informed consent process. However, they are individuals with their own will, preferences and rights, and international law is evolving to recognise this.

The traditional solution for an adult lacking decision-making capacity has been to appoint a guardian or legal representative to consent on their behalf. Under this model of substitute decision-making, a doctor or court would first determine that the person lacks capacity and then another person (the guardian, family member or doctor) would make decisions in the best interests of the patient. This approach prioritizes protection but risks overriding the person's own wishes. In the past, it was common for people with intellectual disabilities or advanced dementia to be completely excluded from decision-making: decisions were simply made for them, not with them.

Modern human rights law has begun to challenge this paternalistic model. The CRPD, adopted in 2006, marked a paradigm shift. Article 12 of the CRPD declares that people with disabilities have the right to equal recognition before the law, which essentially means that mental or intellectual disability does not deprive a person of legal capacity. The CRPD requires States to move away from substitute decision-making and towards systems of supported decision-making (Gordon et al., 2022, p. 6002). In other words, rather than automatically relinquishing decisions to a guardian, the person should be given whatever support they need to make their own decisions to the best of their ability. This can include providing information in plain language, using visual aids, involving a trusted support person or advocate, and providing additional time.

The CRPD Committee (the expert body monitoring implementation) has emphasized that substitute decision-making is incompatible with the principles of the CRPD (Dute, 2015, pp. 315–320). In its first general comment, the Committee stressed⁷ that mental capacity (the ability to make decisions) is not the same as legal capacity (the right to make decisions) (Waddington & McSherry, 2016, pp. 279–304). Historically, many systems have conflated the two – if a person was deemed intellectually incapable of making decisions, they were deprived of the legal right to

⁷ Committee on the Rights of Persons with Disabilities, General comment No. 1 (2014) on Article 12: Equal recognition before the law, adopted at the Eleventh session, 31 March–11 April 2014, UN Doc. CRPD/C/GC/1, para 13.

decide. The CRPD rejects this: even if a person's decision-making capacity is impaired, their legal right to decide remains (Bartlett, 2012, pp. 752–778). States must therefore abolish substitute decision-making regimes and develop alternatives to supported decision-making. In practice, this led to guardianship laws being reviewed worldwide. Some countries have introduced supported decision-making arrangements – for example, in parts of Canada and Australia, an adult can appoint a supporter to help them interpret and communicate their decisions without usurping their decision-making entirely (Korać Graovac & Čulo, 2011).

However, this vision is challenging to realise. There will always be extreme cases – for example, people with profound cognitive impairment or advanced dementia – who, even with all possible support, are unable to formulate decisions about critical treatment. International law recognises that special safeguards may be necessary in such situations (Sorta-Bilajac, 2010). For example, Article 7 of the UNESCO Declaration on Bioethics states that if a person is incapable of giving consent, he or she must be afforded special protection by law.⁸ The earlier Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991) similarly required that any decision declaring a person incapacitated should be made by an impartial tribunal and reviewed regularly.⁹ In practice, this means that if a guardian is to make a decision, it should genuinely reflect what the patient would want if they were able to speak. This is often referred to as the surrogate decision standard: decisions are based on the patient's known values and preferences, rather than simply on what the doctor or guardian believes is best.

An example is the use of advance directives for future incapacity. Many jurisdictions allow people to write advance directives for health care, or wills, stating their preferences for treatment in the event that they are later unable to give consent. In the case of cognitive degenerative diseases such as Alzheimer's, this can be a powerful tool for self-determination. Advance directives are increasingly recognised in legislation and bridge the gap between consent and protection: care is guided by the patient's own voice, rather than the paternalistic decisions of others (Chatham et al., 2025, pp. 1524–1531). In Europe, the legal recognition of advance directives

⁸ UNESCO, Universal Declaration on Bioethics and Human Rights, adopted on 19 October 2005 by the General Conference of UNESCO at its 33rd session.

⁹ United Nations General Assembly, Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, adopted on 17 December 1991 by General Assembly Resolution 46/119, annex, OHCHR.

varies considerably. Germany is a good example - since 2009, the German Civil Code (§ 1901a BGB) explicitly recognises advance directives (Patientenverfügung) as binding, provided they address specific medical situations and interventions (Wiesing et al., 2010, pp. 779–783). France also strengthened the legal standing of advance directives through the Claeys-Leonetti law of 2016.¹⁰ This does allow physicians to depart from advance directives in emergencies or when they are deemed inappropriate (Boulanger et al., 2017). The notion of “manifestly inappropriate” under French law is narrow in this case and mostly includes directives drafted in overly general or ambiguous terms or outdated in light of medical progress. In Italy, Law No. 219/2017 introduced the Disposizioni Anticipate di Trattamento (DAT), which formally recognises living wills.¹¹ Denmark maintains a national registry for living wills through the Danish Health Authority, and Finland recognises advance directives through the Act on the Status and Rights of Patients (Forsius et al., 2025). On the other hand, there are several countries – including Poland, Romania, and Slovakia – that still lack legislation on advance directives.

Despite these advances, real-world practice varies. In some countries, full custodial care (where the individual loses all decision-making rights) is still applied to people with intellectual disabilities, sometimes with little regard for their personal wishes. However, this is gradually changing. Many jurisdictions are exploring intermediate steps, such as limited guardianship, shared decision-making schemes, and mandatory consideration of the person’s will and preferences in any decision.¹² In the European context, the CRPD has provided an impetus for revising laws on capacity and consent in order to strengthen the human rights of people with psychosocial or intellectual disabilities (Stavert, 2015). This includes involving people with disabilities in developing policies that affect them, rather than relinquishing decisions solely to experts.

¹⁰ France. (2016). Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie.

¹¹ Italy. (2017). Legge 22 dicembre 2017, n. 219: Norme in materia di consenso informato e di disposizioni anticipate di trattamento. Gazzetta Ufficiale della Repubblica Italiana, No. 12.

¹² For example, Peru with its Legislative Decree No. 1384 in 2018, which establishes supported decision-making; or Ireland with its Assisted Decision-Making (Capacity) Act in 2015 which introduced a tiered system of decision-making supports.

For people with cognitive disabilities, moving beyond the framework of consent means not to erode the person's autonomy too quickly. This requires mechanisms to support their self-determination and using substitute decision-making only as a last resort. The guiding principle is to do what is necessary to help and protect the patient, but no more – always preserving as much of their own will as possible.

2.2 Patients with Psychiatric Disorders

Perhaps the greatest tension between self-determination and compulsory care arises in the field of mental health. Patients with serious psychiatric disorders – such as schizophrenia, bipolar disorder, psychosis, or severe depression – can sometimes have impaired judgment, pose a risk to themselves or others, or even lack insight into their illness. Many countries have mental health laws that allow for involuntary hospitalization or treatment in certain circumstances, usually when the patient is considered dangerous or incapable of making rational decisions due to their mental state. This is an area where the law explicitly contemplates circumventing the usual rules of consent: treating someone against their will in the interests of their own protection or public safety.

Mental health care has historically been relatively paternalistic. Under older standards (some of which persist), a person could be committed to a psychiatric hospital if they were likely to harm themselves or others as a result of their mental illness, or sometimes simply because treatment was considered in their best interests. Once admitted, they could be forcibly treated or subjected to therapy without consent, based on the doctrine that doctors or the court knew what was best for the patient. The European Court of Human Rights (ECtHR), in the 1992 case of *Herczegfalvy v. Austria*, recognized that a psychiatric patient who was incapable of giving consent could, if objectively necessary for the treatment, be treated against their will.¹³ The ECtHR held that “a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading.”¹⁴ This shows that medical paternalism can be justified in the field of mental illness under certain conditions.

¹³ Judgment of the European Court of Human Rights of 24 September 1992, application no. 10533/83, *Herczegfalvy v. Austria*.

¹⁴ *Ibid*, para 82.

However, international law is moving towards a more rights-based approach. As mentioned earlier, the CRPD calls for a fundamental rethink. Disability rights advocates argue that involuntary psychiatric treatment, if based solely on a person's mental disability, is a form of discrimination and violates a person's right to autonomy and integrity. The CRPD does not explicitly prohibit involuntary hospitalization, but its Committee has interpreted Article 14 (liberty and security of person) to mean that hospitalization on the basis of disability is not permissible. In other words, mental illness cannot in itself be a reason to lock someone up or to render treatment without the person's consent (Bartlett, 2012). The Committee and other UN experts (including the Special Rapporteur on torture) have even called for an "*absolute ban of forced psychiatric interventions*" and to explore alternative solutions.¹⁵ This is a dramatic departure from older thinking, which essentially called for an end to the routine use of involuntary hospitalization and forced treatment.

Despite reforms, the reality remains that involuntary treatment is still practiced in most regions of the world, and there is a debate about how far it should go. On the one hand, there is the ethical argument of therapeutic necessity: if someone is in the midst of a psychotic episode, perhaps suicidal or incapable of recognizing reality, are we really respecting their autonomy by respecting their refusal of treatment? On the other hand, the use of force in medicine, even for supposedly good reasons, can be deeply traumatic and violate human dignity.

Recent research and policy trends are focused on minimizing coercion. For example, the World Health Organization's QualityRights initiative promotes voluntary and community-based mental health care, eliminating practices such as long-term confinement or isolation.¹⁶ Some countries are investing in community-based crisis services (mobile crisis teams, crisis homes) that can respond to psychiatric emergencies in a more collaborative manner, hopefully reducing the need for involuntary hospitalizations. Programs such as Open Dialogue (originating in Finland)¹⁷ focus on intensive, patient-centered therapy early in psychosis, involving

¹⁵ Office of the United Nations High Commissioner for Human Rights, Committee on the Rights of Persons with Disabilities opens ninth session, Press release. Retrieved from: <https://www.ohchr.org/en/press-releases/2013/04/committee-rights-persons-disabilities-opens-ninth-session> (accessed: April 15, 2023).

¹⁶ World Health Organization, WHO QualityRights initiative – improving quality, promoting human rights, Knowledge Action Portal. Retrieved from: <https://www.knowledge-action-portal.com/en/content/who-qualityrights-initiative-improving-quality-promoting-human-rights> (accessed: January 24, 2026).

¹⁷ Council of Europe, Open Dialogue Model – Finland and internationally, Community-Based Initiatives, Human Rights and Biomedicine. Retrieved from: <https://www.coe.int/en/web/human-rights-and-biomedicine/open-dialogue-model>

the patient and their social network in decision-making from the start – reports suggest that this leads to less medication use and possibly fewer cases of involuntary treatment. A study from 2025 found that evidence-based interventions reduce coercive measures by 20-60% (Rojnic Kuzman, Fiorillo & Beezhold, 2025, p. e174).

Caring for psychiatric patients without their consent is a delicate balancing act. A fundamental human rights principle is that any deviation from the patient's expressed wishes must be absolutely necessary and proportionate and used only when no less severe measure could prevent serious harm. Moreover, even if treatment is provided without consent, the patient should be involved to the greatest extent possible – informed about what is happening and their views should be taken into account. International standards now insist that involuntary treatment should not mean a loss of rights and that patients still retain the right to humane treatment.

2.3 Patients with Substance Use Disorders

Addiction is often characterized by compulsive behavior and impaired self-control. This raises the question: if a person with severe alcohol or drug addiction refuses treatment, is that refusal truly informed and free, or is it motivated by the addiction itself? And if it is motivated by compulsive behavior, should the State or family intervene?

In many countries, the standard approach is that adults with addictions are considered capable of making their own decisions about their health, despite their illness, unless there is a clear state of incapacity.¹⁸ In practice, this means that a person addicted to opioids or alcohol cannot generally be forced to undergo treatment simply because they continue to abuse substances. The principle of autonomy applies: they have the right to refuse treatment, even if this decision is detrimental to their health. However, there are important exceptions. Several jurisdictions have enacted laws allowing for the involuntary hospitalization of people with substance use disorders in certain circumstances. For example, in the United States, as of a few years ago, 37 states and the District of Columbia had laws allowing

biomedicine/community-based-initiatives/-/asset_publisher/VE1niSrFa8t0/content/l-approche-du-dialogue-ouvert-finlande-et-niveau-international (accessed: January 24, 2026).

¹⁸ Mostly Western European jurisdictions - in England, Northern Ireland, Scotland and Wales, for instance, involuntary treatment cannot be based exclusively on the use of drugs or alcohol and must be combined with a mental health condition that places the individual or others at significant risk of harm.

for involuntary hospitalization for substance abuse or alcoholism.¹⁹ These laws typically require a showing that the person's substance use poses a serious and imminent risk to themselves or others (for example, repeated near-fatal overdoses or a pregnant woman whose continued drug use is endangering her fetus). In Sweden, the LVM Act (*Lag om vård av missbrukare i vissa fall*) enables compulsory closed care of adults with substance use disorders (Reitan, 2016, pp. 60–69). In the Australian State of New South Wales, the Involuntary Drug and Alcohol Treatment Program, established in 2012, permits detention for treatment of individuals who lack the capacity to make decisions about their substance use, and includes discharge supports transferring individuals to community care for up to six months (Ritter & Stooze, 2016, p. 138). In several Canadian provinces, mental health legislation permits involuntary treatment when substance use co-occurs with a mental health disorder (O'Reilly & Gray, 2014, pp. 65–67).

Family members or doctors can ask the court to commit the person to treatment for a limited period of time, even if the person refuses help. Significantly, however, even when such laws exist, they are rarely used. In the approximately 40% of U.S. states that have provisions for civil commitment to a drug treatment facility, studies have found that they are never or rarely used (Christopher et al., 2015). Many families and even judges do not use this avenue, either because they are unaware of the law or because they are reluctant to override the person's will unless absolutely necessary. The common view is that unless the addiction has led to criminal activity or an acute medical emergency, treatment should remain a choice.

In some countries, particularly parts of East and Southeast Asia and Latin America, there are extreme examples where people who use drugs are rounded up and placed in compulsory detoxification camps or rehabilitation centres without due process (Bazazi, 2018, pp. 1064–1065). These centres have been criticised for abuse – reports by human rights organisations describe how some of these facilities use forced labour or degrading treatment in place of evidence-based care (Zamudio, Chávez & Zafra, 2015).

¹⁹ Hazelden Betty Ford Foundation, Involuntary commitment for substance use disorder, Addiction Research. Retrieved from: <https://www.hazeldenbettyford.org/research-studies/addiction-research/involuntary-commitment> (accessed: January 24, 2026).

Another critical perspective comes from public health research: forced treatment for addiction may not be effective and may even be harmful. Studies suggest that involuntary interventions for substance use are generally less effective than voluntary treatment and may carry risks (Bazazi, 2018, pp. 1064–1065). One risk, for example, is that forcing someone to abstain without their consent can reduce their tolerance for drugs; upon release, if they relapse (since they have not truly embraced recovery), they face a higher risk of overdose. Given these factors, many experts say the emphasis should be on strengthening voluntary pathways to addiction treatment (Chlebcová, Boleková & Višňovská, 2019). This includes making treatment accessible, affordable, and removing stigma so that people are more likely to seek help on their own.

In seeking a balance between self-determination and protection for addicts, several proposals have emerged. One is to include a capacity assessment in addiction cases: to determine whether a person's decision-making is truly so affected by their substance use that they are essentially unable to make decisions (similar to an incapacity test). In rare cases, severe changes in the brain caused by substances can render a person temporarily incapable of rational decision-making, which may justify a substitute decision-maker (similar to severe delirium or intoxication in the emergency room). However, these cases are likely to be the exception. Another proposal is to use court-supervised treatment agreements – e.g., drug courts, where individuals agree to undergo treatment as an alternative to criminal sentences (with some element of coercion, since the alternative is prison, but at least the person has some choice when choosing treatment over prison).

It is important to respect the personhood of addicts. The principle of “do no harm” applies. Any measure beyond consent should be demonstrably more beneficial than harmful. Given that involuntary treatment can have the opposite effect, the threshold for its use must be high and supervision strict. Self-determination should be recognised and used wherever possible.

2.4 Children and the Elderly

Two age-defined groups deserve special discussion: minors (children and adolescents) and elderly patients. Both groups often fall into the high-risk category regarding healthcare decisions, but for very different reasons – the former primarily

due to legal status and adulthood, the latter often due to medical frailties.

2.4.1 Children and Adolescents

In the case of children, the law generally does not recognize full autonomy. Minors (usually under 18) cannot give legally binding consent to most medical treatments. Instead, consent is given by a parent or legal guardian on the assumption that they will act in the child's best interests (Barzó, 2023). However, this does not mean that children have no say. Modern paediatric ethics supports the concept of consent – even if it is not legally required, children who are old enough to understand should be included in discussions and their wishes should be respected to an appropriate extent (Katz, Webb & the Committee on Bioethics, 2023). For example, a 7-year-old child may not choose to undergo chemotherapy, but doctors will explain it to him in simple terms and find out if he agrees; a 16-year-old child, although still a minor, may have sufficient maturity to make certain decisions about his care in collaboration with his parents and doctors.

International human rights law, through Article 12 of the CRC, states that children have the right to express their views freely in all matters affecting them, and these views should be given due weight in accordance with the child's age and maturity. This means that the views of a mature adolescent on medical treatment should not be lightly ignored. Many countries have adopted laws or policies that recognize mature minors – for example, a 16-year-old – can consent to or refuse certain treatments without parental intervention if they are considered mature enough (as is the case in some jurisdictions for decisions regarding mental health counseling or contraceptive services). In England and Wales, the landmark House of Lords decision in *Gillick v West Norfolk and Wisbech Area Health Authority* established that a child under 16 is legally competent to consent to medical treatment if they possess sufficient maturity and intelligence to understand the nature and implications of the proposed treatment – a standard now widely known as Gillick competence.²⁰

However, there are limitations. If a minor (or their parent) refuses treatment that is clearly life-saving or necessary, the State can intervene. Courts around the world have repeatedly ordered treatment of children against the will of their parents: a

²⁰ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112 (HL).

common scenario is when parents refuse a blood transfusion for their child on religious grounds (e.g. Jehovah's Witnesses) or when a teenager with cancer wants to stop painful treatment, but doctors believe that he or she is curable. In such cases, judges apply the best interests of the child test. A child's right to life and health may override the normal rule of parental authority. For example, the *Supreme Court of Canada in AC v. Manitoba* (2009)²¹ upheld a forced blood transfusion for a 14-year-old Jehovah's Witness, emphasizing that the child's welfare is paramount.

These interventions beyond consent (or beyond parental consent) are a form of protective paternalism in law. But they are fraught with ethical dilemmas. The key is that they are absolutely necessary: society should override the decision of a family or minor only in extreme situations where the child's life or long-term health is seriously at risk.

Children in healthcare have the right to protection and participation. We go beyond simple consent (since children cannot legally consent) by using a surrogate decision-maker, but we should also seek to hear the child's voice. The international community is urgently calling for a balance in which we gradually extend the child's autonomy as they mature (in CRC terminology - evolving capacities), while protecting them from serious harm.

2.4.2 Older Patients

At the other end of the age spectrum, we find older patients who often face threats to self-determination. Aging itself does not diminish a person's rights – an 80-year-old has the same right to consent as a 30-year-old. The Inter-American Convention on the Protection of the Human Rights of Older Persons (2015) explicitly states that every older person has the inalienable right to free and informed consent in matters of health.²² This was partly a response to prevalent age discrimination in healthcare, where the choices of older patients could be ignored or overridden.²³ The

²¹ Judgment of the Supreme Court of Canada of 26 June 2009, *A.C. v. Manitoba* (Director of Child and Family Services), 2009 SCC 30, [2009] 2 S.C.R. 181.

²² Inter-American Convention on the Protection of the Human Rights of Older Persons, adopted on 15 June 2015 at the 45th Regular Session of the General Assembly of the Organization of American States, entered into force on 11 January 2017.

²³ American Bar Association, Building the case for a convention on the rights of older persons, *Bifocal* Vol. 46 Issue 3. Retrieved from:

Convention clearly states that age alone is not a reason to bypass consent – older people must be treated as autonomous subjects.

However, many older people face cognitive decline (such as Alzheimer's disease or other forms of dementia) or other disabilities that may affect their decision-making. In these cases, these issues overlap with the previous discussion of cognitive disabilities. An older person who is no longer mentally competent falls under the same frameworks of guardianship or supported decision-making. The problem is that conditions like dementia are progressive – someone may be capable today, but not in a year. This is why advance care planning in geriatrics is so important. Encouraging older adults to express their values and wishes regarding future health care (through advance directives, durable powers of attorney for health care, etc.) is a key proposition for ensuring that their self-determination is respected, even if they later lose the capacity to make decisions.

Another common scenario is an elderly patient who is mentally competent but is subjected to subtle pressure or coercion. Elder abuse can take the form of relatives pressuring the older person to refuse certain treatments (perhaps to save money or expedite an inheritance) or to agree to things they do not want. Protecting autonomy in this case may require screening and advocacy – healthcare providers must be alert to signs that the older person's consent is not truly voluntary. Some jurisdictions have ombudspersons for the elderly or patient advocates who can intervene if an elderly patient's rights are being violated in a healthcare or long-term care facility.²⁴

Both children and older people show that age requires an individualized approach beyond the simple model of adult consent. In case of older people, we should strongly support their autonomy and intervene only when medical incapacity truly requires it, and even then, we follow the person's advance directives or likely wishes. In both groups, the principle is to respect the human dignity of the person at every stage of life – children must not be considered merely objects of medical decisions and older people as passive recipients of care. International human rights frameworks require that the inherent rights and wishes of every person, whether they are 8 or 80, be taken into account.

https://www.americanbar.org/groups/law_aging/publications/bifocal/vol46/vol46issue3/conventiononolderpersonsrights/ (accessed: January 24, 2026).

²⁴ For example, Hungary, Finland, Norway, Sweden.

3 Moving Forward: Innovative Approaches and Recommendations

Protecting high-risk patients while simultaneously respecting their self-determination is a challenge. Based on the previous analysis of legal frameworks and ethical considerations, we present key proposals that transcend a simple consent model for vulnerable patients.

States should reform laws to replace guardianship and surrogate decision-making with networks of supported decision-making. This means legislating formal mechanisms for patients with cognitive or psychosocial disabilities to receive assistance with decision-making. This will meet the requirements of the CRPD and keep the patient at the center of decision-making. Several jurisdictions have already taken significant steps in this direction. Peru (Legislative Decree No. 1384 of 2018) and Colombia (Law 1996 of 2019) have abolished guardianship for persons with disabilities and replaced it with supported decision-making frameworks. Ireland's Assisted Decision-Making (Capacity) Act 2015 introduced a tiered system of supports – from decision-making assistance to co-decision-making and, only as a last resort, decision-making representation. In Germany, the 2021 reform of guardianship law (Betreuungsrechtsreform) reinforces the principle that assistance must be oriented to the will and preferences of the person concerned. All of these examples show that the transition from substitute to supported decision-making is legally feasible. Empirical evidence also supports this. A 2024 systematic review of 140 studies on supported and shared decision-making interventions in mental healthcare found favourable outcomes across several dimensions. According to a 2024 study, facilitated treatment planning was associated with reductions in suicidal ideation, improvements in recovery measures such as empowerment, knowledge and quality of life, and a reduction in the use of involuntary hospitalisation (Francis, Hazelton & Wilson, 2024).

Health systems must support and respect advance directives, living wills and health care powers of attorney. Patients at risk of losing capacity (due to progressive illness or temporary incapacity) should be assisted in documenting their treatment preferences while they are able to do so. Legislation should ensure that these instructions are binding on healthcare providers (within reason and the law). This extends the right to self-determination to periods when the patient cannot actively consent. There are several great examples of this already happening in certain

jurisdictions. Germany's Civil Code has recognised binding advance directives since 2009, France's Claeys-Leonetti law of 2016 strengthened patients' rights to anticipatory decision-making, and Italy's Law No. 219/2017 introduced advance treatment provisions. India's Mental Healthcare Act of 2017 introduced the right to make advance directives in the context of mental health treatment, which is a significant innovation in the Global South.

Another suggestion is to develop clear protocols to assess a patient's decision-making capacity whenever a non-standard situation regarding consent arises. Capacity assessments should be conducted by qualified professionals, be specific to the decision in question, and be free from bias (not assuming incapacity solely on the basis of age, disability, or addiction). Regular reassessment is important, as capacity may fluctuate (e.g., a psychiatric patient may regain capacity after an acute episode).

It is also important to always utilize a the least restrictive alternative that can achieve the health goal, consistent with human rights principles. If some form of coercion is deemed necessary (e.g., temporary detention for emergency detoxification of an overdose victim), it should be as finite as possible, with a clear therapeutic purpose.

Any legal framework that allows for involuntary treatment (of mental illness, addiction or other conditions) should include robust safeguards. For example, independent advocacy services or ombudspersons should be available to represent the patient's voice (for example, mental health advocates who visit psychiatric wards to ensure that patients understand their rights and can defend themselves against abuse).

Naturally, any treatment provided without the patient's consent must meet the highest standards of care and ethics. In particular, in the case of psychiatric and addiction treatment, evidence-based practices should be mandatory. Coercive environments often fall short in quality, which is unacceptable. If the State forces someone into treatment, it has a duty to provide effective and humane treatment, not just detention.

Hospitals and health care facilities should use ethics committees or case conferences in complex situations where a patient's decision-making capacity or refusal of treatment is in question. These committees can bring multidisciplinary perspectives to ensure that any decision that overrides the patient's wishes is carefully considered and made only if it is truly justified. This introduces a level of accountability.

Some advocates are seeking an explicit "right to supported decision-making" or "right to mental capacity" in national laws, in line with Article 12 of the CRPD, to cement a change in legal culture. Others are proposing a human right to avoid undue interference, which would require doctors to demonstrate necessity before acting against the patient's will.

Implementing these recommendations will undoubtedly require changes in legislation, policies and professional practice. It may also require resources – decision-making support networks or community-based care alternatives can be resource-intensive. However, the investment is worth it if it leads to a more ethical health care system that respects the rights of vulnerable populations.

4 Conclusion

"Beyond consent" does not mean abandoning consent – it means building on informed consent to address the realities of vulnerable patients. High-risk patients challenge us to refine the way we view autonomy. International law is very clear on this: every person, regardless of disability or vulnerability, has the right to self-determination and to be treated with dignity. Concurrently, human rights frameworks recognize the need to protect people from serious harm, even when they are unable to protect themselves.

The way forward is through an approach that is inclusive, innovative and compassionate. We need to embrace solutions such as supported decision-making, advance directives and peer support to minimise the need for coercion. It is an approach that does not see autonomy as a black and white switch (on or off) but as a spectrum that we can enhance with support. If protective intervention is needed, it must be customized, transparent and accountable. In short, autonomy and protection are not mutually exclusive: we provide the best protection by empowering patients' voices wherever possible.

In practice, a health system that truly goes beyond consent will have fewer lawsuits over forced treatment and more bedside conversations about what patients want, fear and value. It will not treat consent as a formality (signing a form), but as an ongoing dialogue that adapts even when patients cannot speak for themselves.

The measure of a humane health system is how it treats the most vulnerable. High-risk patients deserve protection and respect. Protection should not be used as a code word for paternalism, but as a commitment to caring for patients in a way that is consistent with their own humanity and will. This is what healthcare beyond consent means – a system in which even those who cannot say “yes” or “no” are heard.

Legal Acts, Case-law

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Povzetek v slovenskem jeziku

Sodobno zdravstvo temelji na načelu prostovoljne privolitve, ki je podlaga za avtonomijo in samoodločanje pacientov. Vendar ima ta model zelo jasne omejitve, ko se uporablja pri visoko ogroženih in ranljivih pacientih, katerih sposobnost odločanja je omejena. Študija preučuje, kaj se skriva za privolitvijo v zdravstvu, in zastavlja vprašanje, kako lahko pravni sistemi zaščitijo visoko ogrožene paciente, ne da bi pri tem ogrožali njihovo dostojanstvo, avtonomijo in človekove pravice. Analiza uporablja primerjalno-pravni pristop. Opira se na mednarodne instrumente in nacionalne primere iz različnih pravnih tradicij. Članek zastopa stališče, da ranljivost ne sme služiti kot utemeljitev za paternalizem ali nekontrolirano prisilo. Preseganje soglasja ne pomeni opustitve avtonomije, temveč njeno ponovno opredelitev na način, ki zagotavlja samoodločanje in zaščito tistih, ki so v sistemih zdravstvenega varstva najbolj ranljivi.