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# The Neglect of Persons with Severe Brain Injury in the United States: An International Human Rights Analysis

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## Abstract

Brain injury contributes more to death and disability globally than any other traumatic incident. While the past decade has seen significant medical advances, laws and policies remain stumbling blocks to treatment and care. The quality of life of persons with severe brain injury often declines with unnecessary institutionalization and inadequate access to rehabilitation and assistive technologies. This raises a host of rights violations that are hidden, given that persons with severe brain injury are generally invisible and marginalized. This article highlights the current neglect and experiences of persons with severe brain injury in the United States, analyzing the rights to life, health, benefit from scientific progress, education, freedom of expression, community, family, and equality.

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## Introduction

Brain injury contributes more to death and disability globally than any other traumatic incident.[1] Each year, there are approximately 69 million reported cases worldwide, but numbers may be even higher due to severe under-reporting.[2] In the United States, brain injury is the leading cause of death and disability among young people.[3] In fact, researchers refer to traumatic brain injury as a "silent epidemic."[4]

While medical and scientific advances mean that the lives of persons who sustain severe brain injuries can be saved, quality of life post-injury often decline because of unnecessary institutionalization in long-term care facilities and a subsequent lack of access to rehabilitation and technologies that can assist with the injured person's communication and community reintegration. Although severe brain injury seems to be solely a medical problem, many of the barriers to quality care post-injury are rights violations and can be addressed through law and policy interventions.[5]

Indeed, the care and treatment of persons with severe brain injury raises questions of fundamental rights and human dignity. Current medical practice all too often results in violations of the rights to life, health, benefit from scientific progress, education, freedom of expression, community, family, and equality. However, violations of the rights of persons with severe brain injury are often hidden since such persons are not in a position to advocate for themselves, and their family members may be burdened by grief and the demands of care.[6] Even within the disability community, the issues affecting persons with severe brain injury are largely invisible and marginalized.

This article provides an international human rights analysis of the experiences of persons with severe brain injury, highlighting their neglected rights. With severe brain injury being an overlooked topic in the human rights field, this article seeks to contribute to scholarship and advocacy in this area by providing a conceptual framework of key rights at stake through an interdisciplinary analysis of law, neuroscience, and clinical practice. While this article focuses on the United States, brain injury is a global concern, and this analysis is relevant to many other countries. The first section describes severe brain injury, outlines available medical treatments, and discusses clinical, legal, and policy barriers to care. The second section analyzes the experiences of persons with severe brain injury against the guarantees of the Convention on the Rights of Persons with Disabilities (CRPD), which sets the global standard regarding the rights of persons with disabilities, as well as the International Bill of Human Rights, consisting of the Universal Declaration of Human Rights, International Covenant on Civil and Political Rights (ICCPR), and International Covenant on Economic, Social and Cultural Rights (ICESCR).[7] Finally, the third section provides recommendations to advance the rights of persons with severe brain injury and address current gaps in treatment and care.

## Severe brain injury and available treatments

Thanks to advances in medical knowledge, persons who in the recent past would have died because of severe brain injuries now often survive, many with differing degrees of disability, including disorders of consciousness (DOCs). Scientific knowledge of DOCs has evolved over the decades, and recent years have seen the development of an evidence-based practice, as well as updated terminology and standards of care published in 2018.[8] Yet much remains to be done. To date, there is no comprehensive epidemiology of patients with these conditions; instead, the prevalence is estimated to be several hundred thousand people in the United States, although these data are likely flawed methodologically.[9]

DOCs include the vegetative state and minimally conscious state (MCS). The vegetative state is "a condition of wakeful unconsciousness" in which a patient's eyes may be open but there is no evidence of consciousness.[10] The MCS, first defined in 2002, is "a condition of severely altered consciousness characterized by minimal but definite behavioral evidence of self or environmental awareness."[11] A person enters the MCS after being in a coma or vegetative state, and manifestations of consciousness are inconsistent.[12]

Scientific research has demonstrated that brain states are not static; rather, they evolve over time.[13] Indeed, with existing technology and medical knowledge, and with proper diagnosis and appropriate medical interventions, improvement and recovery are possible for persons with DOCs. Presently, two-thirds of persons with a severe brain injury regain consciousness, and just over a fifth of persons in the MCS regain functional independence when they receive the standard of rehabilitative care.[14] As the state of science advances, there is hope for persons with DOCs who have not yet regained functional independence.

There are some promising investigational neurotechnologies in development that may assist a person with a DOC in regaining consciousness and some abilities. For example, a randomized clinical trial has shown that some drugs, such as amantadine, when administered to persons with DOC accelerate the recovery of consciousness.[15] Prescribing amantadine off-label to accelerate the recovery of consciousness is now the standard of care for persons with DOCs in rehabilitation.[16] Additionally, neuromodulation is another investigational avenue being explored. This includes deep brain stimulation, vagal nerve stimulation, transcranial magnetic stimulation, hyperbaric therapy, and directed ultrasound.[17]

Despite this promise, most persons with a DOC do not have access to necessary rehabilitation, much less basic medical care. Many die of preventable illnesses such as bedsores, urinary tract infections, and pneumonia.[18] Equally critically, many are denied an accurate diagnosis. Researchers have found that over 40% of persons in the MCS in chronic care following traumatic brain injury are misdiagnosed as being in the vegetative state.[19] When improperly diagnosed as vegetative, persons fail to receive appropriate medical care and rehabilitation, and are instead housed in long-term care facilities.[20] And tragically, when patients are thought vegetative and insensate, they may also be denied pain medication.[21]

## Barriers to treatment as human rights violations

Some of the issues that persons with severe brain injury and subsequent DOCs face post-injury have medical and technological solutions. If inaccurate diagnosis is because clinicians are unaware of the existence of the MCS, how to properly diagnose it, or that amantadine should be administered to try to induce consciousness, then the solution is better education and clinical training. Additionally, misdiagnosis may be because the person with severe brain injury is "covertly" conscious, unable to physically indicate their consciousness.[22] In this case, the solution is access to skilled clinicians trained to administer a neuropsychological exam known as the "coma recovery scale-revised," which is the most effective way to evaluate the presence of the MCS.[23]

What is less obvious, but perhaps more consequential, is how law and policies can negatively affect the lives of persons with severe brain injury. In the United States, for example, persons with DOCs may not be able to afford necessary rehabilitation because health insurance may not reimburse patients for the required length of rehabilitation.[24] In contrast to other wealthy countries, the United States lacks an affirmative right to health care.[25] Regulatory policies governing drugs and devices may also cause delays in getting effective treatments from bench to bedside.[26] Additionally, laws that protect persons with disabilities from discrimination and mandate accommodations, although applicable to persons with DOC, may not be applied or enforced.[27] Indeed, recent empirical scholarship has shown that physicians are often ignorant of their affirmative duties to accommodate their patients with disabilities when providing health care.[28] Furthermore, when persons with brain injury assert their legal rights under federal disability law, even when they have legal victories, there are few resulting changes in practice.[29] Finally, specific groups of persons with brain injuries may also be neglected.[30] For example, while legislators have taken action to help veterans with traumatic brain injuries gain access to necessary health care, administrative agencies have not followed through to ensure this access.[31] Thus, legal intervention is also required to improve the lives of persons with DOCs.

Clinical care, laws, and policies all need to be improved to ensure that persons with severe brain injury and subsequent DOCs are not neglected, but instead have access to appropriate medical care and thus have the opportunity to regain consciousness and be reintegrated into their communities.[32] The basic human dignity of persons with severe brain injury, as well as their legal entitlement to appropriate treatment and care, needs to be recognized.

The concepts of equality and dignity are at the heart of human rights. Indeed, the Universal Declaration of Human Rights establishes the "inherent dignity" of every person as "the foundation of freedom, justice and peace in the world."[33] Similarly, the preambles of various international human rights treaties identify dignity as the basis for other rights.[34] The CRPD, adopted in 2006, takes a significant step in affirming the dignity of persons with disabilities and their standing within the human community, asserting that "discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person."[35]

These principles and affirmations must be applied to persons with severe brain injury so that this population is no longer invisible, marginalized, or disregarded. Appropriate treatment and rehabilitation for persons with severe brain injury is not just a scientific or medical issue but a matter of respect for fundamental human dignity.[36] Framing the current subpar treatment of persons with DOCs in terms of human rights violations may provide an ethical and legal catalyst for change. This remainder of this section discusses the human rights implications for persons with DOCs.

### *Right to life with dignity*

In some cases, health care providers may view continued medical treatment for persons with DOCs as futile. But such a lack of support for a family's desire to continue care may infringe on the right to life when patients have the potential to benefit from medical advancements.[37] As both the ICCPR and CRPD recognize, "Every human being has the inherent right to life."[38] The CRPD further calls on states to "take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis."[39]

A family's desire for ongoing treatment of a person with a DOC after a severe brain injury is often out of sync with a health care system that typically recommends that care be withheld or withdrawn upon the loss of consciousness after an injury or illness or wrongly analogizes the loss of consciousness occurring with severe brain injury to a terminal illness.[40] There is a negative bias within society and among health care providers against persons with DOCs since, in many cases, the loss of consciousness reflects the last stage of a long, drawn-out illness.[41] For example, in Alzheimer's disease, terminal cancer, and late-stage congestive heart failure, the loss of consciousness often signals the final stage of the disease.[42] However, brain injury is generally accompanied by unconsciousness at the outset, which could be the first step toward recovery.[43] Therefore, to equate the loss of consciousness from brain injury with the loss of consciousness from a degenerative or progressive disease is a flawed analogy since these illnesses have distinct trajectories.

A life with disability, even with severe brain injury, can still have great value to the person, as well as others. As the mother of a woman with severe brain injury explained, "Heather is going to be different, but I don't think that doesn't mean she won't be a wonderful daughter, friend, sister, and we won't enjoy her for the rest of her life."[44] The right to life for such persons requires respect.

### *Right to health*

Current inadequate treatment and care of persons with severe brain injury and DOCs also violates their right to health. As set out in the ICESCR, everyone has the right "to the enjoyment of the highest attainable standard of physical and mental health."[45] The CRPD further clarifies that "persons with disabilities have the right to the enjoyment of the highest standard of health without discrimination on the basis of disability."[46] As the United Nations (UN) Committee on Economic, Social and Cultural Rights has explained, the right to the highest attainable standard of health entails quality health services that are available, acceptable, and accessible "to all, especially the most vulnerable or marginalized sections of the population."[47]

All too often, however, persons with severe brain injury receive brilliant and life-saving emergency care only to be abandoned by the health care system as they transition to the chronic care sector. Because the prevailing medical and cultural view is that the injured brain cannot recover and regain lost functionality, resources for care thus fall off after acute survival is assured, and the marginalization of persons with a DOC begins.[48] This marginalization and neglect include premature discharge, warehousing in inadequate facilities, misdiagnosis, and denial of rehabilitation.[49]

Patients with severe brain injury and subsequent DOCs are often discharged from the hospital while still unstable and transferred to long-term care facilities that are unequipped to provide appropriate care for this patient population, particularly patients in the MCS who require therapeutic engagement.[50] Further, as discussed previously, studies show that the diagnostic error rate of patients with DOCs in nursing homes is over 40%, in part because nursing homes often fail to recognize improvement in MCS patients.[51] These patients are wrongfully diagnosed as vegetative when they are, in fact, in the MCS.[52]

This misdiagnosis is often because before a patient shows overt behavioral improvements that evidence consciousness, the brain demonstrates structural changes.[53] Despite a bedside evaluation that may not show evidence of consciousness, neuroimaging may show network activation in MCS patients consistent with the ability to sustain emotion, thought, and language; progress in patients with severe brain injury may not be observable given that recovery from these injuries is particularly long and variable.[54] Measuring progress solely by motor function thus discriminates against patients who cannot yet move or speak. Patients may remain misdiagnosed for years while families struggle to obtain an accurate diagnosis. The CRPD, however, requires "early identification and intervention as appropriate."[55] Doing so is difficult, however, not only because these patients are often in long-term care facilities rather than hospitals or rehabilitative facilities where they would have neuropsychiatric health care specialists and neuroimaging equipment, but also because there is still a substantial lack of information regarding DOC prognosis, resulting from a gap in studies on patient rehabilitation and recovery.[56]

Moreover, despite the CRPD-enshrined right to "comprehensive habilitation and rehabilitation services and programmes," the denial of rehabilitation is a common problem for persons with severe brain injury and DOCs worldwide.[57] According to a 2011 report by the World Health Organization, 42% of countries surveyed adopted no rehabilitation policies, 50% had passed no rehabilitation legislation for people with disabilities, and 40% had not adequately established rehabilitation programs.[58] In the United States, the way that Medicare local coverage determination decisions are made may result in denying approval for rehabilitation for persons with DOCs, and private health insurance may differ on the scope and extent of rehabilitation coverage.[59] In sum, although the CRPD specifically "prohibit[s] discrimination against persons with disabilities in the provision of health insurance" and the "discriminatory denial of health care or health services," and the US Affordable Care Act also contains a non-discrimination section, in practice, many patients with DOCs experience discrimination in health care coverage and delivery.[60]

### *Right to benefit from scientific progress*

Persons with severe brain injury are not adequately benefitting from scientific advances. The ICESCR recognizes the right of everyone "[t]o enjoy the benefits of scientific progress and its applications."[61] The CRPD elaborates on states' obligation "to undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communication technologies, mobility aids, devices and assistive technologies."[62] Moreover, it requires states to "promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation."[63]

Persons with severe brain injury have a right to benefit from scientific progress, including medications, rehabilitation, and neuroprosthetic technologies that may restore their ability to communicate and connect with others. Neuroprosthetics—devices that doctors implant into a patient's brain or onto their head in order to "supplement the input or output of the nervous system"—include artificial retinas, cochlear implants, and surface electromyography electrodes. Neuroprosthetics can help patients regain the ability to see and hear and re-enable the use of paralyzed limbs, and thus can be beneficial to persons with severe brain injury who acquire such disabilities.[64]

Indeed, assistive technologies are critical to the realization of a human rights of persons with severe brain injury. As the UN Special Rapporteur on the rights of persons with disabilities explains, for many persons with disabilities, access to assistive technologies and support services "constitutes a precondition for the respect of their inherent dignity and the full and equal enjoyment of all human rights and fundamental freedoms."[65] Such access is also recognized as essential to the non-discriminatory treatment of persons with disabilities under the Americans with Disabilities Act, the United States' federal disability law.[66]

However, thus far, scientific developments have had little impact on the experiences of patients with DOCs who lack access to necessary medication, rehabilitation, and neuroprosthetics.[67] This may be because in the United States, health care providers and insurers do not recognize their legal obligation under the Americans with Disabilities Act to provide existing technology and medical interventions to accommodate patients with severe brain injury in order to help them communicate with their providers to the extent they are able.[68] Further, promising neurotechnologies may never make it to the market, because of both research-related and regulatory hurdles.[69]

Indeed, we have yet to take even the first step of collecting epidemiological data and conducting studies necessary to develop assistive technologies and guide policy, a requirement under international law.[70] Under the CRPD, states must "undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies" to protect basic rights.[71] The Special Rapporteur on the rights of persons with disabilities likewise emphasizes the importance of data collection.[72] Simply put: without a count, *you don't count.*

### *Right to education*

Persons with severe brain injury are often deprived of necessary rehabilitation and thus the ability to develop their full potential, which implicates the human right to education. The ICESCR enshrines "the right of everyone to education" for the "full development of the human personality and the sense of its dignity."[73] The CRPD mandates "an inclusive education system at all levels and lifelong learning" to enable "development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential."[74] The United States provides free public schooling for children through the age of majority in recognition of the importance of minimum education. And with regard to children with disabilities, the United States requires "a free [and] appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living."[75] Thus, both international and US domestic law recognize the need for appropriate education for people to reach their full potential.

The purpose of rehabilitation can be considered similar in key respects to the purpose of education, critical to the development of persons with severe brain injury. As noted previously, most MCS patients lack access to rehabilitative technologies and "remain sequestered in nursing homes, incompletely diagnosed … at the margins of society."[76] According to emerging scientific evidence, the brain regenerates through axonal growth, just as it does in its initial development.[77] It may thus make sense to view brain injury recovery through a developmental frame and to view rehabilitation as analogous to education.[78] Accordingly, persons with severe brain injury should have access to rehabilitation, which, like education, functions to help them reach their full potential.[79]

However, the amount of rehabilitation currently provided to patients with brain injury is meager.[80] Post-acute rehabilitation needs to be of sufficient scope, duration, and intensity for injured persons to regain lost skills and learn new compensatory strategies. Additionally, as with the education of children, this process takes months and years rather than weeks.

### *Right to freedom of expression*

Persons with severe brain injury may not have access to tools to assist them with communication. Communicating wishes is an important element of autonomy and self-determination fundamental to personhood and human rights. Communication is also a component of the right to freedom of expression. Freedom of expression is recognized by the ICCPR and includes the "freedom to seek, receive and impart information and ideas of all kinds."[81] And under the CRPD, states must "take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion."[82] Freedom of expression also ties into the first guiding principle set out by the CRPD: "[r]espect for the inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons."[83]

For persons with severe brain injury, like all persons, the ability to communicate is critical. As one of this paper's authors has previously asserted, "If they cannot communicate, we do not know they exist."[84] Communication for many persons with severe brain injury is now possible through the use of assistive devices.[85] These devices may enable such persons to express their preferences and connect with others. When, as all too often occurs, persons with severe brain injury are not given the tools to communicate, they are denied the right to freedom of expression.[86]

### *Right to community*

The ability to communicate is not only critical to freedom of expression but also essential to forming relationships and being part of a community, which many persons with severe brain injury and DOCs are denied.[87] The CRPD recognizes the "equal right of all persons with disabilities to life in the community."[88] States must take measures to ensure their "full inclusion and participation in the community" and "to prevent isolation or segregation." [89]

Community is not only a physical place; rather, it can also be created through communication and relationships with others. Restoring communication for persons with severe brain injury enables their reintegration into family and society, while failure to diagnose and sustain consciousness relegates such persons to continued exile.[90] As the mother of one patient with brain injury explained, "But if she can't communicate, then there is no way for her to share the life of the mind with everyone else."[91] When MCS patients are enabled to communicate, their community can be rebuilt.

Additionally, persons with severe brain injury should have access to a community of peers. Housing young patients with severe brain injury in nursing homes serving older persons with degenerative disease segregates them from their peers and deprives them of opportunities. Rather, these young patients should be cared for in facilities with patients of their generation, where the focus is not on support during decline but on facilitating rehabilitation and progress.

### *Right to family*

Having a family is a fundamental human right, including for persons with disabilities such as severe brain injury. The ICCPR sets out the "right of men and women of marriageable age to marry and found a family," echoed by the CRPD, and the ICESCR requires the "widest possible protection and assistance … to the family, which is the natural and fundamental group unit of society."[92] The CRPD exhorts states to "take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships."[93] The UN Committee on the Rights of Persons with Disabilities has further criticized the denial of legal capacity with no provision for support in decision-making as leading to the deprivation "of many fundamental rights," including the right to marry and found a family and parental rights.[94]

The current financing mechanisms of the US health care system, however, do not protect the family relations of persons with significant disabilities but rather contribute to tearing them apart. In couples where one partner suffers from brain injury, for which the costs of care can be financially ruinous, partners may be forced into a "Medicaid divorce" to qualify for public health insurance while protecting family assets. As one spouse lamented, "This country doesn't allow a catastrophe like this to take care of someone without wiping out a family."[95] Health care regulations in the United States compound medical tragedies, severing relationships. After the divorce, the former caretaking spouse may no longer be legally entrusted with decision-making and care. Instead, this role may pass to the patient's other family members. This can be heartbreaking for the couple. One husband, eventually forced into a "Medicaid divorce," recounts comforting his wife with brain injury:

> *I hold her, tell her I love her, and tell her I'm going to find whatever help there is out there and I'll never abandon her. Because I took our marriage vows very seriously … I won't abandon you. I say, the last breath I take will be taking care of you.*[96]

This is in stark contrast with the policies of other developed countries, which provide universal health insurance with negligible out-of-pocket costs. In Canada, for instance, patients without private insurance who have sustained a traumatic brain injury enjoy free access to inpatient acute care and rehabilitation. However, care, largely financed by tax revenues from individual provinces, may entail some disparities for residents from different localities.[97] Significantly, the financing of health care in Canada does not require families to dissolve in order to receive care for significant disabilities such as severe brain injury.

In addition to the right to marry, persons with severe brain injury have the right to continuing contact and a relationship with their children. The CRPD recognizes this right and sets out that "[i]n no case shall a child be separated from parents on the basis of a disability."[98] However, in cases of separation or divorce, a person with severe brain injury may be completely cut off from any children. A woman whose adult daughter suffers from a DOC recounts the family's legal struggles to ensure contact between her daughter and her minor children, who are in the custody of an ex-spouse who refuses to allow them to see their mother because she has a DOC. She highlights that this contact with her children may be important not only to the children's well-being but also to her daughter's cognitive recovery.[99] To comply with the CRPD, states must "ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child."[100]

### *Right to equality*

Equality is a core human rights principle that is often violated with respect to persons with severe brain injury, such as when they are legally denied the right to make their own decisions or not able to access assistive devices that would aid them in communicating with others, as discussed earlier. The first article of the Universal Declaration of Human Rights proclaims, "All human beings are born free and equal in dignity and rights."[101] The ICCPR and Universal Declaration of Human Rights further establish that all persons "are equal before the law and are entitled without any discrimination to equal protection of the law," which the CRPD echoes.[102] The equality enshrined in these international instruments is substantive rather than a formal requirement of identical treatment.[103] In fact, as the UN Human Rights Committee has recognized, equality may necessitate "affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination."[104] In this vein, the CRPD states that "[i]n order to promote equality and eliminate discrimination," states should "take all appropriate steps to ensure that reasonable accommodation is provided."[105] Moreover, "[s]pecific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination."[106]

Closely linked to equality is fundamental dignity and "the right to recognition everywhere as a person before the law" under the various international instruments.[107] As the Committee on the Rights of Persons with Disabilities has clarified, this includes the enjoyment of "legal capacity on an equal basis with others," integral to "the capacity to be both a holder of rights and an actor under the law."[108] Instead of substituting for the decisions of persons with disability, the state has the responsibility to provide the support needed for the exercise of legal capacity.[109] Moreover, a "person's mode of communication must not be a barrier to obtain support in decision-making, even where this communication is non-conventional, or understood by very few people."[110] However, as the committee has explained:

> *Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry, or establish a civil partnership, and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.*[111]

While US federal disability law (the Americans with Disabilities Act) is also meant to ensure equality and non-discrimination in employment and places of public accommodation, this law may have limited effect in assuring equality for persons with severe brain injury if actors such as health care providers do not recognize their legal duty to accommodate persons with disabilities, there is a lack of understanding about what constitutes proper accommodations, or persons with disabilities do not have the legal resources to assert their rights.[112] Significantly, many US states undermine the legal capacity and fundamental rights of persons with cognitive disabilities. While some states' laws allow for supported decision-making for a person with a cognitive impairment such as severe brain injury, where a person with a cognitive disability retains legal capacity while also receiving assistance in making decisions on the basis of their preferences and interests, most state laws necessitate the complete transfer of decision-making authority to surrogates or a guardian.[113] This often negatively affects other important rights, such as the right to benefit from scientific progress. For instance, laws that deny persons under guardianship the right to participate in clinical research may also mean that persons with severe brain injury under guardianship do not have access to cutting-edge therapies being studied in clinical trials.[114] Laws that deny legal recognition and capacity thus violate the fundamental equality and basic rights of persons with severe brain injury, requiring amendment.

## A path forward

The current lack of access to treatment and rehabilitation for persons with severe brain injury violates their fundamental rights to human dignity, life, health, benefit from scientific progress, education, freedom of expression, community, marriage and family, and equality. Compliance with international human rights law requires the following:

- data collection on persons with severe brain injury
- improved diagnosis
- an end to unnecessary institutionalization in long-term care facilities
- access to rehabilitation and communication technologies, covered by health insurance
- access to a community of peers
- support for families to stay together

While full achievement of economic and social rights is subject to resource constraints, these rights bring certain immediate obligations, and governments must take steps for their progressive realization "to the maximum of available resources."[115] The right to health contains a minimum core, immediately binding, which includes non-discriminatory access to health care and the equitable distribution of health facilities, goods, and services.[116] The UN Special Rapporteur on the rights of persons with disabilities provides specific guidance on resource implications. She explains that "obligations of immediate effect," even if resources are scarce, include "the elimination of discrimination in the exercise of this right, … securing access to social protection and ensuring a minimum essential level of benefits for all persons with disabilities and their families."[117] It is important to recognize that that some technologies and rehabilitation treatments for persons with severe brain injury may be costly. Such interventions need not be provided all at once, but governments must take steps toward their provision to satisfy their obligations.

The minimum core of the right to health requires the adoption of national health strategies and plans of actions with benchmarks to measure progressive realization. These national strategies and plans must further give particular attention to vulnerable and marginalized groups, such as persons with severe brain injury.[118] Currently, with a 41% misdiagnosis rate, persons with severe brain injury do not receive a basic standard of care available to others. Indeed, many are not even receiving basic medical care or treatment at all.[119] Thus, national health strategies and plans must address this gap to protect basic rights. As the UN Special Rapporteur on the rights of persons with disabilities notes, "[t] o guarantee progressive realization of the right to social protection, States should formulate strategies and plans that include realistic, achievable and measurable indicators and time-bound targets, designed to assess progress in its implementation."[120]

Accordingly, states at the very least must eliminate discrimination in care and create strategies and action plans to meet the needs of persons with severe brain injury. Now that we understand the gravity of this situation and the vulnerability of individuals with severe brain injury and DOCs, we are ethically and legally obliged to act and advocate to address current neglect.

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