

**Submission to the Human Rights Committee Advisory Committee call for inputs on neurotechnology and human rights**

**July 2 2023**

**Neurotechnology and the rights of persons with disabilities**

**Introduction:**

In recent years, advancements in neurotechnology have opened new possibilities for individuals with disabilities, promising to enhance their quality of life and promote inclusivity. However, as we explore the potential benefits of neurotechnology, it is crucial to navigate the ethical and human rights implications surrounding ableism and the right to mental integrity. We hope the HRC Advisory Committee will carefully consider the intersection of neurotechnology, disabilities, ableism, and the right to mental integrity, highlighting the need for a balanced approach that respects the dignity and autonomy of individuals with disabilities.

IDA's primary concern is that the paradigm shift of the Convention on the Rights of Persons with Disabilities, social model of disability, and the work of CRPD (principles, standards, or the text itself) is fully reflected in the work of the Advisory Committee. This is always a concern when considering medical technology, with all the risks entailed by the outdated and inappropriate medical model of disability and ableism. It would be essential to integrate a CRPD-perspective on medical technology, as articulated by the Special Rapporteur on the rights of persons with disabilities in her report A/HRC/43/41. We are deeply concernedthat ableist ways of thinking, reinforced by the medical model of disability, have historically privileged prevention and cure over all other responses to disability, leaving persons with disabilities with limited opportunities to be included and participate in society.

On this basis, we wish to stress the following 4 points:

1. Society must embrace disability as a positive aspect of humanity the cultural and societal challenges posed by ableism, and accelerating a cultural transformation of the way society relates to the difference of disability
2. It is critical to actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to medical and scientific practice concerning them, including law reform, policy development and research. National bioethics committees must consult and include persons with disabilities in their work;
3. Stressing the importance of awareness-raising in tackling deeply rooted stereotypes, negative attitudes and stigma, which can lead to discrimination against persons with disabilities
4. Note the challenges that arise from power imbalance with medical and large research or private sector organizations, with particular steps must be taken to address this imbalance. There is a need to think carefully about what is counted as ‘expertise’, recognising the priority that should be given to lived experience from a human rights-based approach

**Opportunities**

**Right to enjoy the benefits of scientific progress:** We note General Comment No. 25 of the Committee on Economic Cultural and Social rights, and the attention paid to persons with disabilities, in which the Committee said that “Persons with disabilities have suffered deep discrimination in the enjoyment of the right to participate in and to enjoy the benefits of scientific progress and its applications, either because of severe physical, communication and information obstacles to access basic and higher scientific education and careers, or because the products of scientific progress do not take into account their specificities and particular needs”. Below we list some of the technology that as been suggested as potentially offering benefits to persons with disabilities, including in the area of habilitation and rehabilitation.

* Brain-computer interfaces (BCIs) that allow individuals with paralysis to control prosthetic limbs or communicate through their thoughts.
* Deep brain stimulation (DBS), a neurotechnology technique, has shown promising results for persons with Parkinson's disease and epilepsy
* Transcranial magnetic stimulation (TMS) and transcranial direct current stimulation (tDCS) have been investigated for their ability to enhance attention, working memory, and learning capabilities.
* Techniques like functional magnetic resonance imaging (fMRI) and electroencephalography (EEG) allow scientists to observe brain activity in real-time, aiding in the understanding of brain function, cognitive processes, and neural issues..
* Spinal cord stimulation (SCS), a neurotechnology approach, involves implanting electrodes near the spinal cord to alleviate chronic pain.

These potential benefits must be considered with the challenges listed below, with regulatory and policy frameworks taking account of CRPD obligations and standards.

**Challenges**:

**Ableism:** While neurotechnology holds immense potential, it is crucial to challenge ableism within its development and implementation. Ableism is a discriminatory ideology that favors able-bodied norms, perpetuates stereotypes, and devalues individuals with disabilities. It is essential to ensure that the development and utilization of neurotechnology prioritize the needs, preferences, and rights of persons with disabilities, rather than reinforcing existing ableist paradigms. This entails involving individuals with disabilities in the design process, promoting accessibility, and avoiding stigmatization or objectification. Strengthened efforts on awareness raising under Article 8 of the CRPD should be required.

**Avoiding Enhancement Pressure:** Related to the above point, neurotechnology should not be solely driven by the goal of enhancing human capabilities, and must be put in the context of understanding and respecting diversity as per the Convention on the Rights of Persons with Disabilities. Pressuring individuals to pursue enhancement interventions risks perpetuating ableism and undermining the right to mental integrity.

**Psychosocial Implications**: Neurotechnology has the potential to alter an individual's cognitive and emotional processes. Unregulated use without proper ethical guidelines and monitoring may expose persons with disabilities to undue psychological risks. Improper use of neurotechnology could lead to unintended psychological consequences. These risks could disproportionately affect persons with psychosocial disabilities.

**Respecting Mental Integrity:** The right to mental integrity is a fundamental human right that safeguards individuals' autonomy and protects them from unwanted intrusion into their mental processes. Before and during when someone is accessing neurotechnology related services, it is imperative that mental integrity is respected. Individuals must have the freedom to choose whether or not to engage with neurotechnological interventions and to control their personal data. Consent, privacy, and ensuring that neurotechnology remains a tool for empowerment rather than coercion are paramount.

**Exploitation and Discrimination:** Unregulated neurotechnology could exacerbate existing inequalities and discrimination faced by persons with disabilities. The availability and accessibility of neurotechnological interventions could be limited to certain socioeconomic groups, creating disparities in access to treatment and exacerbating social inequities. Moreover, the unscrupulous use of neurotechnology may lead to increased discrimination or exploitation based on an individual's neural characteristics, thereby infringing upon their right to equality and non-discrimination.

**Access and Affordability**: Ensuring equitable access to neurotechnological interventions is crucial. Measures should be taken to address financial barriers and disparities in healthcare access, enabling individuals with disabilities from diverse backgrounds to benefit from these advancements.

**Ethical Concerns:** Neurotechnology raises complex ethical questions surrounding the manipulation and alteration of the human mind. Unregulated use of these technologies without clear ethical frameworks and guidelines may lead to the abuse of power by individuals or institutions. This could result in unauthorized mind control, forced cognitive enhancements, or non-consensual experimentation, all of which threaten the mental integrity and dignity of persons with disabilities. Establishing independent ethical review boards to oversee the use of neurotechnology can help ensure that ethical standards are maintained, including monitoring for potential abuses and protecting against unauthorized experimentation or coercion.

**Informed Consent**: Informed consent is the cornerstone of ethical neurotechnological interventions. Persons with disabilities should have access to comprehensive information about potential risks, benefits, and alternatives. The consent process should be accessible, accommodating diverse communication needs and ensuring that individuals understand the implications of their choices. Discussion of ‘informed consent’ is critical but must be meaningful and genuine. Looking at the history of other medical practices, often this is not genuine, and various loopholes and forms of coercion are used, in a way profoundly violating of human rights, while still using the language of rights. The task ahead is to develop appropriate regulation/legal frameworks at the domestic level, on this basis of existing international human rights treaties which are fully capable and mandated to consider the impact of new technology.

We remind the Advisory Committee of the history of lobotomies, under which tens of thousands of such operations were carried out on the basis of medical advice, disproportionately on women and children. One doctor even received a Nobel Prize for his work in this area in 1949. We know understand these to be extremely grave human rights violations. It would be naïve to think that that we are free from such risks today. The same underlying ableist ideas, of the need to “fix people” underlies much of modern neurotechnology. We note that draft WHO-OHCHR Guidance on mental health legislation suggests a need to have an outright ban on irreversible psychosurgery

**Privacy and Data Security:** Neurotechnology often involves the collection and processing of sensitive personal data. Strict privacy measures must be implemented to protect individuals from unauthorized access or misuse of their neural information. Robust data security protocols should be established, and individuals must have control over their own data, including the ability to withdraw consent and request deletion.

**Conclusion**

While neurotechnology holds potential positive impact for persons with disabilities, the unregulated use of these technologies poses significant risks to the rights of persons with disabilities, including the right to mental integrity. To mitigate these risks, it is essential to establish comprehensive regulations, ethical frameworks, and oversight mechanisms. By doing so, society can harness the benefits of neurotechnology while ensuring the protection of the rights of persons with disabilities. Developing regulatory frameworks consistent with CRPD standards, and the Advisory Committee carefully considering a CRPD-based perspective in this area of work is essential for it to proceed in a positive and rights-based way in the Human Rights Council, including by collaborating with other relevant mandate holders.