

Solutions Follow Perceptions: NBIC and the Concept of Health, Medicine, Disability and Disease

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Nanotechnology, the art of manipulating materials on an atomic or molecular scale,¹ enables a new paradigm of science and technology that sees different technologies converging at the nanoscale, namely (a) nanoscience and nanotechnology; (b) biotechnology and biomedicine; (c) information technology; and (d) cognitive science (“NBIC” (nano-bio-info-cogno)). This paradigm derives from the fact that living systems are governed by molecular behavior at the nanometer scale, where chemistry, physics, biology, and computer science all now converge.

The National Nanotech Initiative (US) envisions applications for the converging of NBIC in areas such as the environment, energy, water, weapons and other military applications, globalization, agriculture and health (more efficient diagnostics and genetic testing; cognitive enhancement; life extension; enhancing human performances in general),² each of which comes with its own sales pitches, social consequences, problems and implications. This paper will look at the area of NBIC-medicine and its relationship to disabled people.

NBIC - Health, Disabled People and Improving Human Life

“What do we want from NBIC? How do advances in NBIC change and influence our self-perception, our self-identity, the quality of our lives and our ability to pursue ‘the good life?’” Answering these questions requires an examination of the complex interdependent fabric of perceptions, values

and choices within different cultural, economic, ethical, spiritual and moral frameworks. In the case of NBIC-medicine it is important to investigate the understanding that society and individuals have of the concept of health and disease. Furthermore, as so-called disabled people are often highlighted as the beneficiaries of NBIC-medicine products, we have to ask ourselves what perception of disabled people and what concept of disability, a concept more contentious than is commonly recognized, guides NBIC research and development, and what role disabled people are playing in this process.

What Is Health? What Is a Disease? What Methods to Use to Remedy the Situation?

Three main models for health and disease (the medical, the social and the transhumanist) can be identified. Within the medical model of health and disease, health is characterized as the normative functioning of biological systems, and disease is seen as the sub-normative functioning of biological systems. Medical interventions on the level of the individual are seen as the remedy of choice.

On a global scale, the disability-adjusted life year (DALY) has emerged as a new measure of the burden of disease. However, it becomes increasingly clear that the DALY concept that is so far based on the purely medical model of health and disease is flawed. DALY treats, for example, paraplegia in developed and developing countries the same,



independent of societal parameters. In developed countries many people with paraplegia have wheelchairs and the loss of mobility is therefore reduced. In developing countries many do not have wheelchairs, and their mobility is severely restricted. Furthermore, wheelchairs alone are of no use unless the environment is designed to cater to them. So the provision of a wheelchair in one context would not have the same effect that it would have in another. It seems we need an additional model or a broader understanding of the concepts of health and disease.

The social model of health and disease still follows the sub-normative functioning of a person, but it differs from the medical model by questioning the exclusive focus on medical remedies of individuals. According to the *Jakarta Declaration on Leading Health Promotion into the 21st Century*,³ pre-requisites for health are peace, shelter, education, social security, social relations, food, income, empowerment of women, a stable eco-system, sustainable resource use, social justice, respect for human rights and equity. Above all, poverty is the greatest threat to health. The Ottawa Charter states: “[p]olitical, economic, social, cultural, environmental, behavioural and biological factors can all favour health or be harmful to it.”⁴

If we look at the primary conditions leading to a global burden of disease it seems that this burden can be diminished a lot by including environmental, societal and other contextual interventions. In the poorest regions of the world, childhood and maternal underweight, unsafe sex, unsafe water, sanitation and hygiene, indoor smoke from solid fuels and various micronutrient deficiencies are major contributors to loss of healthy life. In both developing and developed regions, alcohol, tobacco, high blood pressure and high cholesterol were major causes of disease burden. The four addictive disorders: nicotine addiction, calorie addiction, alcohol abuse and illicit drug abuse account for more than one-third of the disabilities as measured by DALY by the Oklahoma State Board of Health.⁵ It seems we need a fusion of the social model and the medical model of health and disease.

Advances in NBIC give life to a third, the transhumanist, model of health and disease, where health is characterized as

the optimum functioning of biological systems and interpreted as the concept of feeling good about one’s abilities, functioning and body structure. Disease in this case is identified in accordance with a negative self-perception and a suboptimum functioning. Medical and technological interventions on the level of the individual are seen as remedies in this model. As it will be increasingly difficult to distinguish between NBIC ‘health products’ that lead to ‘therapies towards the norm’ and ‘therapies which will exceed a norm’, improving norms and adding new abilities to human beings will be inevitable, leading to the need to include the transhumanist model of health and disease in our thinking.

In the case of NBIC-medicine it is important to investigate the understanding that society and individuals have of the concept of health and disease.

NBIC and the self-identity of disabled people

The concept of health and disease is one variable in deciding how to use NBIC. Another variable is how disabled people perceive themselves. Parallel to the three models of health and disease, three main models

describing the self-identity of disabled people, their relation to so-called non-disabled people, and the usage of NBIC can be identified.

Disabled people can opt to be seen as inherently defective and subnormal, in need of being fixed by NBIC to a societal norm of the so called non-disabled, (e.g. giving legs to amputees) which will be as good or worse than biological legs (the patient/medical model, mM).⁶ Alternately, they can opt not only to be fixed to a norm but also to be enhanced, augmented above the norm (e.g. giving bionic legs to amputees, which work better than the ‘normal’ biological legs), following the transhumanist vision of the so-called non-disabled people who believe that every human body is defective (the transhumanist model, tM).⁷ Thirdly, they can opt to see their biological reality as a variation of being not in need of fixing, but in need of having the physical environment, the interaction with the physical environment and the societal climate changed to accommodate their biological reality (e.g. giving wheelchairs to amputees and making the physical environment wheelchair accessible, or using teleportation devices if they are ever developed) (the social justice social model, sM).⁸



NBIC and Public Perception of Disabled People

A third variable in deciding how to use NBIC is the public perception of disabled people. Disabled people are normally perceived as having a low quality of life, as subnormal people, as people with a medical deficiency.⁹ With this negative perception of disabled people – with legal decisions indicating that disabled people have the obligation to fix themselves,¹⁰ with bioethicists and members of the media¹¹ passively or actively questioning the validity of a social justice identity of disabled people¹² and with the perception that society will never support and accept disabled people with their variation of being¹³ – it comes as no surprise that the development of NBIC applications and the selling of NBIC ‘health products’ focuses mostly on offering disabled people medical solutions (prevention or cure/normative adaptation). While NBIC applications might move towards transhumanist solutions (augmentation, enhancement of the human body), they rarely offer social solutions (adaptation of the environment, acceptance, societal cures of equal rights and respect). Taking into account the above reality, it comes also as no surprise that we do not hear the voice of the disabled around the policy and ethics debate of the governance and research and development of NBIC. And if we hear a disabled person, rarely as it is, it is a disabled person adhering to the medical model of disability. This lack of presence was recognized by the final documents of the 1999 UNESCO World Conference on Sciences,¹⁴ although not much has changed since 1999.

As long as disabled people of all types of identities are not represented in a meaningful way in the policy and ethics debate of the governance and research and development of NBIC, the above NBIC focus will not change with detrimental effects for disabled people in the minority (the developed) and in particular the majority (the developing) countries. It is easy to say ‘we will find a cure for you,’ but the reality is that cures are scarce and far between and even if cures are developed most disabled people will not have access to them. The reality is that only two percent of disabled people in developing countries have access to even basic health care,¹⁵ not to speak of high-tech medicine. Fur-

thermore, the focus on the medical, defective label often leads to pity, rejection, lack of respect, segregation, animal farm ethics¹⁶ and a silenced human rights voice.¹⁷

Slanting the playing field of public policy and the governance of NBIC in such a way that disabled people are forced to accept a certain identity and certain perception of self could be seen as violating the UNESCO *Universal Declaration on Cultural Diversity*,¹⁸ which posits itself as:

Reaffirming that culture should be regarded as the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs.

Many disabled people, people with non-normative body compositions, functioning and abilities, have forged a cultural identity based on a common history of oppression and a common bond of resilience. They see ableism (discrimination based on non-normative abilities, functioning and body structures) as equal to racism, ageism, homophobia and other-isms. Furthermore, disabled people are a social group. This means that this interpretation of cultural diversity entails that disabled people should feel free to choose cultural identities of their choice, whether medical, social, transhumanist or others.

Pushing people to accept a certain identity and discriminating against a cultural minority (the disabled) has interesting similarities with other types of state-sponsored action that are forbidden by international law, such as torture. Article 1 of the *UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 1984*,¹⁹ states:

torture means any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person ...for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.

If NBIC is to benefit societies and its people, we must realize that health and medicine themselves are social constructs.



One form of torture is the destruction of an existing self-identity and replacing it with another one. For example, the brainwashing of prisoners of war is seen as a form of torture. The same kind of brainwashing happens to disabled people. If I constantly tell a person without legs how worthless and defective they are, and that they have to be able to walk on two legs in order to be seen as a human being, and therefore have to wear and use artificial legs, this could be seen as brainwashing and therefore torture. Granted, brainwashing of prisoners is not done by people believing they are doing the prisoners any good, whereas many in the situation of the disabled believe they are in fact acting for the good of the disabled. However, the lines blur if those governing science and technology refuse to accept and act on the sM self-identity of the disabled and instead insist on using a simple mM to characterize their problems and solutions, even if the disabled tell them to look at the sM model to characterize the problems and solutions they face.

NBIC and the Non-Disabled

As it will be increasingly difficult to distinguish between ‘therapies towards the norm’ and ‘therapies which will exceed a norm’, we will see a fusion of the patient/transhumanist identity. If the disabled are allowed to enjoy (or, better say, forced to enjoy) new abilities, whether they are entirely new or incremental improvements of normal abilities, for sure others such as the non-disabled transhumanists want to follow by adding all kind of augmentations to their bodies helping themselves to fulfill their own desires. These non-disabled transhumanists see NBIC as having the potential to free them from the ‘confinement of their genes’ (genomic freedom) and the potential to free people from the ‘confinement of their biological bodies’ (morphological freedom).

The above dynamic can lead to a rat race of abilities, productivity, competitiveness and functioning between individuals and between societies, cultures and countries and to a normative creep where the bell curve is moved towards the right to higher abilities and ‘improvement of the norm’. Disabled people will play a central role in this normative creep. So far people are used to thinking that the ‘subnormal’, the disabled (mM) will be fixed to the existing norm of the non-disabled. However advances in NBIC make this thinking obsolete because the fixes for the ‘subnormal’ the disabled (mM) might give them capabilities that will exceed the non-disabled norm. For example, if we see amputees as defective in need of a fix (artificial legs) there is no way to

negate them access to bionic legs which might allow the amputees to run faster or jump higher than the normal non-disabled people. These legs would be a therapy and an enhancement at the same time. Society might see these initial ‘medical enhancements’ as advantages. They might make them the new higher norm and might want to add these new leg capabilities to people who still have their original legs. This dynamic will contribute to the acceptance of research that seeks to improve the capabilities of normal legs already underway.²⁰

Having, in the end, an untenable ethical divide of using NBIC for medical versus social reasons will not stop this dynamic.

Conclusion

The author opened up the debate around the usage of NBIC in the health arena. The debate around NBIC and health has to become much more multifaceted, losing its adherence to just the medical model of disability, health and disease. If NBIC is to benefit societies and its people, we must realize that health and medicine themselves are social constructs.²¹ The ethics structure around the governance of NBIC has to stop granting ethical approvals based on an arbitrary system which approves applications done for so-called medical reasons but condemns them if done for social reasons, for such a dichotomy is artificial and socially constructed. The debate around the usage of NBIC should look in more detail at what kind of impact NBIC products have on disabled people, their lives, their self-perception and their relation with non-disabled people.

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