The Brave New World of Therapeutic Enhancement and its Impact on People with Disabilities and Those Who Work with Them

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The Wolb Pack

A Collaborative Interdisciplinary Student Research Team

http://www.crds.org/research/faculty/Gregor_Wolbring.html
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Ability Studies: Investigates the cultural dynamic of Ability expectation (want) and Ableism (need)
The term ableism evolved from the disability rights movements in the United States and Britain during the 1960s and 1970s.

However ableism goes beyond body ability expectations.

Ableism also as such is not negative it just highlights that one favours certain abilities and sees them as essential.
Scientific and Technological advancements
Un outil, une machine ce sont des organes, et des organes sont des outils ou des Machines (Canguilhem, 1952).

Tools and machines are kinds of organs, and organs are kinds of tools or machines; translation from (Hacking, 1998)).
The Pack S&T
In addition to cutting potatoes with her prosthetic feet (for a movie), Aimee holds world records in track and has done some runway modeling.

Photos courtesy of Aimee Mulins
www.youtube.com/watch?v=IYWd2C3XVIk
http://www.sarcos.com/
The **Audio** is a featherweight wireless device resting over the vocal cords capable of transmitting neurological information from the brain”. The Audeo from Ambient is also envisioned as a sub-vocal chat device for gaming purposes.
Insects with modified body structures and embedded micro-electromechanical systems (MEMS) have survived to adulthood in a US Defense Advanced Reseach Projects Agency (DARPA) programme.
Converging Technologies for Improving Human Performance: Nanotechnology, Biotechnology, Information Technology and Cognitive Science (NBIC)
Synthetic Biology is
A) the design and construction of new biological parts, devices, and systems, and
B) the re-design of existing, natural biological systems for useful purposes.
Humans that photosynthesize
New biological pathways
Reversal of Aging
Disease Fighting
Implantable living battery for medical device out of electric eel cells.
Beneficial bacterial infections programmed to augment immunity, provide needed vitamins, etc.
cybernetics
self repair bodies
Programmed Organisms
changing behaviour
programmable pets
biological robots
syntho-eukaryotic cell
living self-repairing materials (inhabited by colony of engineered cells)
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Meaning of ...
So far, the very meaning of health and therefore treatment and rehabilitation is benchmarked to the normal or species typical body. We expect certain abilities in members of a species; we expect humans to walk but not to fly, but a bird we expect to fly.

disease/ illness is defined as the species-typical sub-normative functioning of biological systems.

Rehabilitation is a treatment or treatments designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible.
Health in this model is the concept of having obtained maximum (at any given time) enhancement (improvement) of one’s abilities, functioning and body structure beyond species typical boundaries.

Rehabilitation is a treatment or treatments designed to facilitate the process of recovery from injury, illness, or disease to as optimum a condition as possible.
• It will become an increasingly flourishing field of medicine providing enhancement remedies through surgery, pharmaceuticals, implants, and other means (Wolbring 2005),

• this will generate whole new medical jobs, such as ‘body engineers’, ‘body designers’ and ‘body techno-maintenance crews,’
Enhancement model of Disability Adjusted life Years Health Insurance business Right to Health Burden of disease Impairment
What drives the move toward an enhancement vision?
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Converging Technologies for Improving Human Performance: Nanotechnology, Biotechnology, Information Technology and Cognitive Science (NBIC)
The NBIC report used the term productivity over 60 times and the term efficiency 54 times and the term competitiveness 29 times.
For many, enhancements promised by new and more powerful technologies will be seen as a logical extension of what is commonplace today, and it will be increasingly difficult to draw a clear line between their uses for therapeutic purposes and their use for enhancement. (AAAS webpage)
Drivers of Enhancement

- Pools indicate driver for enhancement depends on social status,
- his/her competitive advantage.
- Canton has identified several market pressures
  - 1) global competitiveness;
  - 2) brain drain/depopulation economics;
  - 3) national security concerns; and
  - 4) quality of life/consumer life-style demands. (AAAS webpage)

http://www.aaas.org/spp/sfrl/projects/human_enhancement
“Once you have a way in which you can improve our children, no one can stop it. It would be stupid not to use it because someone else will. Those parents who enhance their children, then their children are going to be the ones who dominate the world.”

—James Watson, 1962 Physiology and Medicine Prizewinner
and some ethicists talk about the obligation to enhance oneself beyond the species-typical

In Germany April 1933, the [Reich Association of the Blind] RBV published Kraemer’s pamphlet Kritik der Eugenik: Vom Standpunkt des Betroffenen (Critique of Eugenics: From the Standpoint of One Affected by It), which is the only well-founded critique of eugenics written until that time in Germany by a disabled person. Kraemer’s project was to unmask the ideological nature of eugenic conceptions of inferiority. He warned against the coming Nazi Sterilization Law and predicted that euthanasia of “useless” persons was the logical consequence of eugenic thinking. Also, he critiqued eugenicists for exaggerating the cost of caring for the impaired, for viewing impaired people as necessarily suffering, and for overemphasizing the importance of productive labor and military fitness.

Climate of achieving Performance Enhancing Drug Compliance in Sport

The likelihood of drug use will be highest when

- a) threat appraisal is low
- b) benefit appraisal is high
- c) personal morality is neutral (e.g. ‘drug use is a personal decision – there are no victims’);
- d) perceived legitimacy of the laws and enforcement agency is low
- e) relevant reference groups are supportive of drug use
- f) high vulnerability on personality factors (e.g. low self-esteem, risk taker, pessimist) (Donovan, Egger, Kapernick, & Mendoza, 2002).
Many disabled people see themselves as not having a positive place within society; feel they do not belong, are not accepted, respected and accommodated for who they are, and are not treated as full citizens.

Disabled people will perceive enhancements as highly beneficial and not immoral.

The relevant support groups very likely will be supportive.

The disabled person is highly vulnerable to the enhancement sales pitches.

Laws and regulations will be seen as having no legitimacy to prevent enhancements, as enhancements will be seen as therapeutic social and otherwise.
The UN Convention on the rights of persons with disabilities (United Nations, 2007) demands that disabled people are given access to assistive devices and the convention does not draw a line between assistive devices that lead to species-typical or beyond species-typical abilities (Wolbring, 2009b).
Governance/Anticipatory governance of S&T
### Governance

- **Anticipatory governance aims to understand the potential social, ethical, and political impacts of emerging discourses**

It entails

- foresight (constructing plausible socio-technical implications),
- integration (bringing together diverse fields such as social sciences and natural sciences),
- engagement (bringing together public citizens, developers, engineers, policy-makers, and other actors to construct conversations around awareness, reaction, and knowledge development and sharing),
- ensemblization which brings together the three elements.

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Question: Which ability expectations drive a given S&T and its governance?
Governance/ Anticipatory governance assume many abilities of the stakeholders

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• **Questions:**
  • Will your future client be enhanced?
  • Will you serve the enhanced ‘healthy’ or the improved ‘impaired’ first?
  • Will you lobby for enhancements beyond the normal for people who are perceived to be “impaired”?
  • Will you lobby against enhancements for the ‘healthy’ due to their impact on the well-being of the so called ‘impaired’?
  • Will you shape the governance of the S&T?
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Conclusion

David Werner
Your turn
Any questions?