

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

**Dr. Gregor Wolbring
Community Rehabilitation and Disability Studies
University of Calgary,**

**Rehabilitation Engineering and Assistive
Technology Society of North America Conference,
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gwolbrin[at]ucalgary.ca

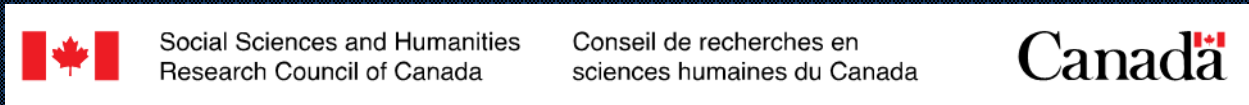
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My Students The Wolb Pack

A Collaborative Interdisciplinary Student Research Team

http://www.crd.s.org/research/faculty/Gregor_Wolbring.s.html





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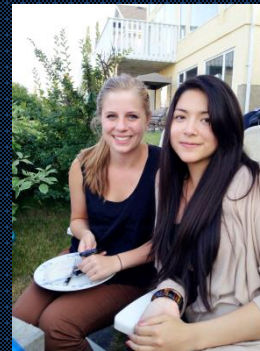
Natalie Ball: Neuro enhancement/Cognitive Enhancement/Eugenics
 Lucy Diep: Brain Machine Interface/Social Robotics/Anticipatory governance
 Verlyn Leopatra Health Consumerism
 Sonum Panesar Bionics
 Jeremy Tynedal Sport
 Sophya Yumakulov: Social Robotics/Artificial Womb

ALUMNI

Natalie Ball
 Alshaba Billawala
 Dana De Bok
 Jenna Galloway
 Verlyn Leopatra
 Brian Litke
 Sonum Panesar
 Theresa Rybchinski
 Camlila Sanchez
 Kayla Schill
 Jeremy Tynedal

Present Group

Dr. Gregor Wolbring
 Dr. Jesse Hendrikse
 Bushra Abdullah
 Rosemarie Breton
 Emily Cha
 Lily Choi
 Jennifer Cheung
 Lucy Diep
 Emily Hutcheon
 Kelsey Lucek
 Rachel Mackay
 Angelica Martin
 Kalie Mosig
 Jacqueline Noga
 Anuya Pai
 Maharaj R
 Eniola Salami
 Kassi Shave
 Melanie Valkey
 Sophya Yumakulov





The Pack **Ability Studies**

**Ability Studies: Investigates the cultural
dynamic of
Ability expectation (want)
and Ableism (need)**



The Pack **Ability Studies**

- 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.



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S&T

Scientific and Technological advancements



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- 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)).



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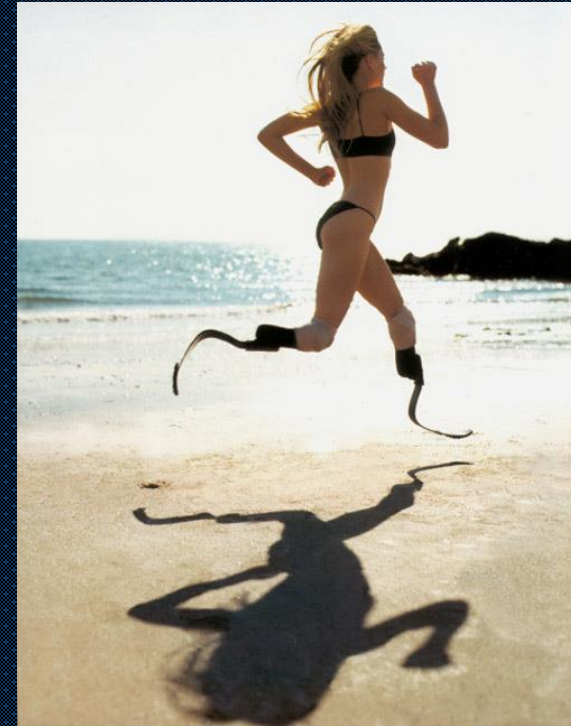
S&T





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S&T

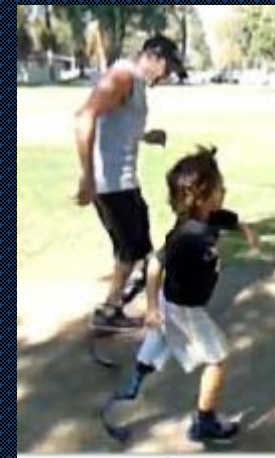


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In addition to cutting potatoes with her prosthetic feet (for a movie), Aimee holds world records in track and has done some runway modeling.

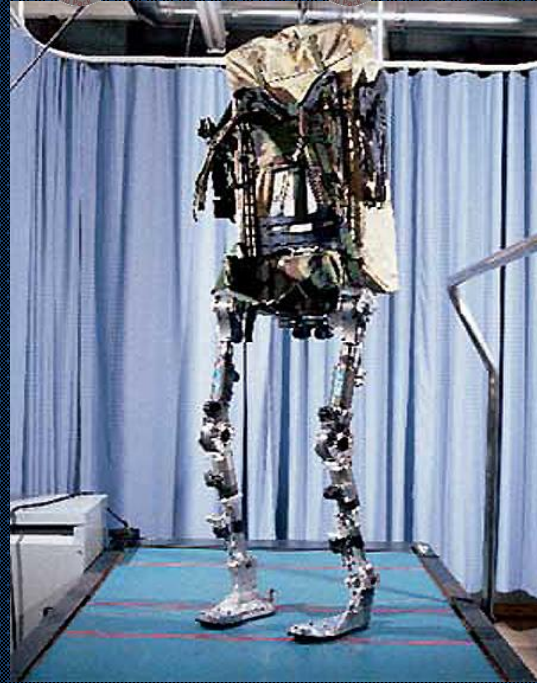
Photos courtesy of Aimee Mullins





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www.youtube.com/watch?v=IYWd2C3XVIk
<http://www.sarcos.com/>



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<http://gizmodo.com/a-mind-controlled-exoskeleton-will-kick-off-2014s-socc-1493046675>



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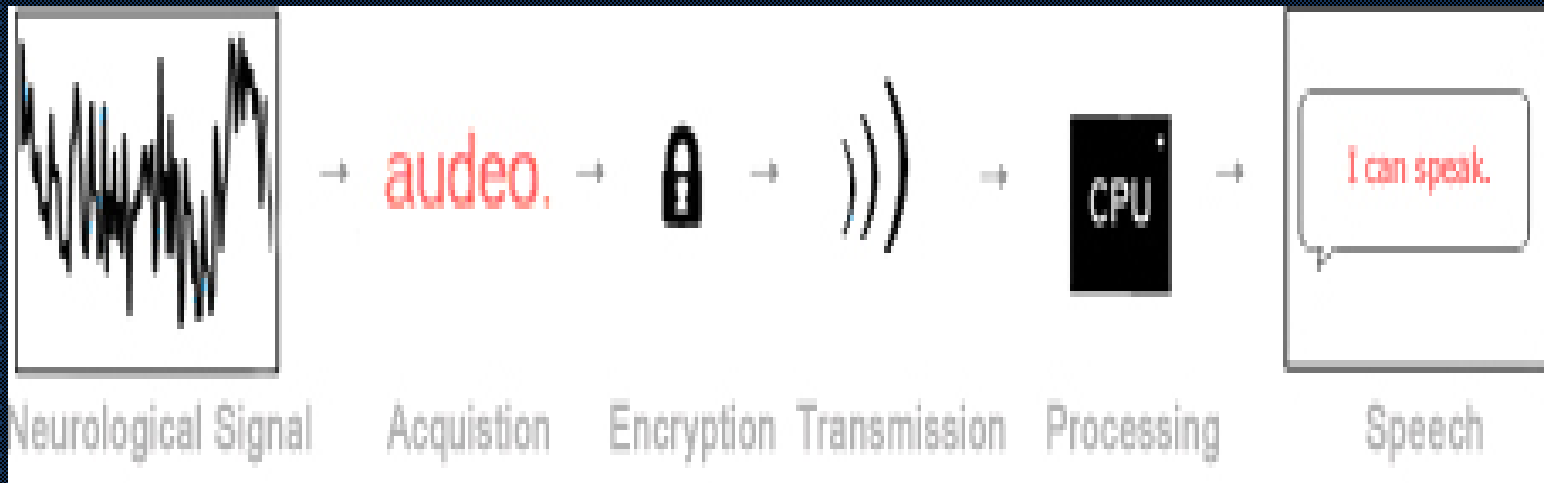




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The Audio is a featherweight wireless device resting over the vocal cords capable of transmitting neurological information from the brain”. The Audeo from Ambient is also envisioned as a sub-vocal chat device for gaming purposes.





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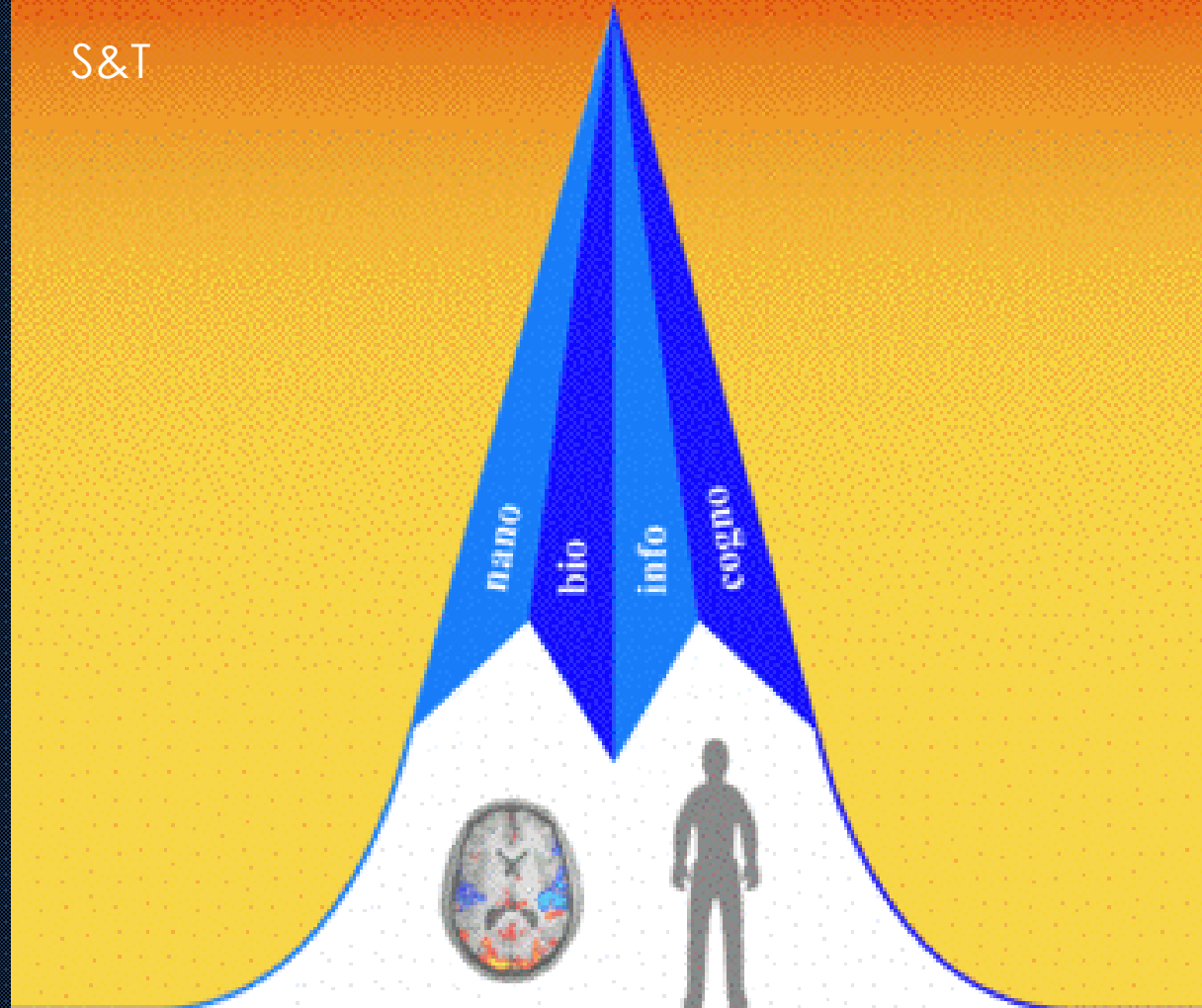


Insects with modified body structures and embedded micro-electromechanical systems (MEMS) have survived to adulthood in a US Defense Advanced Research Projects Agency (DARPA) programme.



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S&T

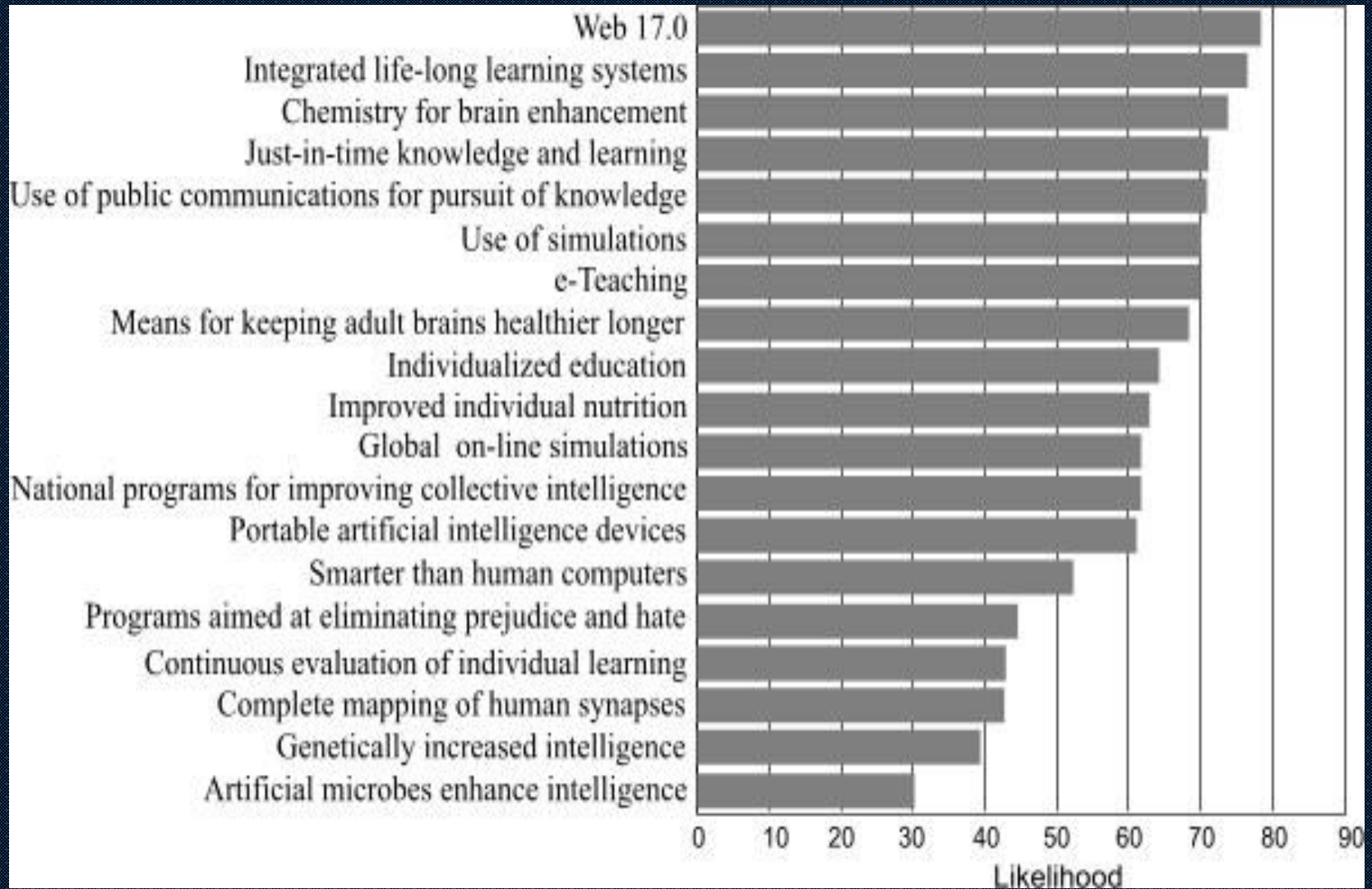


Converging Technologies for Improving Human Performance:
Nanotechnology, Biotechnology, Information Technology and Cognitive Science (NBIC)



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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.



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- 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)



Artificial Womb

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Meaning
of

Meaning of...



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Meaning
of Health and Rehabilitation

- 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**.



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Meaning
of Health and rehabilitation

- 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



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Enhancement Medicine

- 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,'



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Meaning
of

Enhancement model of
Disability Adjusted life Years
Health Insurance business
Right to Health
Burden of disease
Impairment



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Drivers of Enhancement

What drives the move toward a enhancement vision?



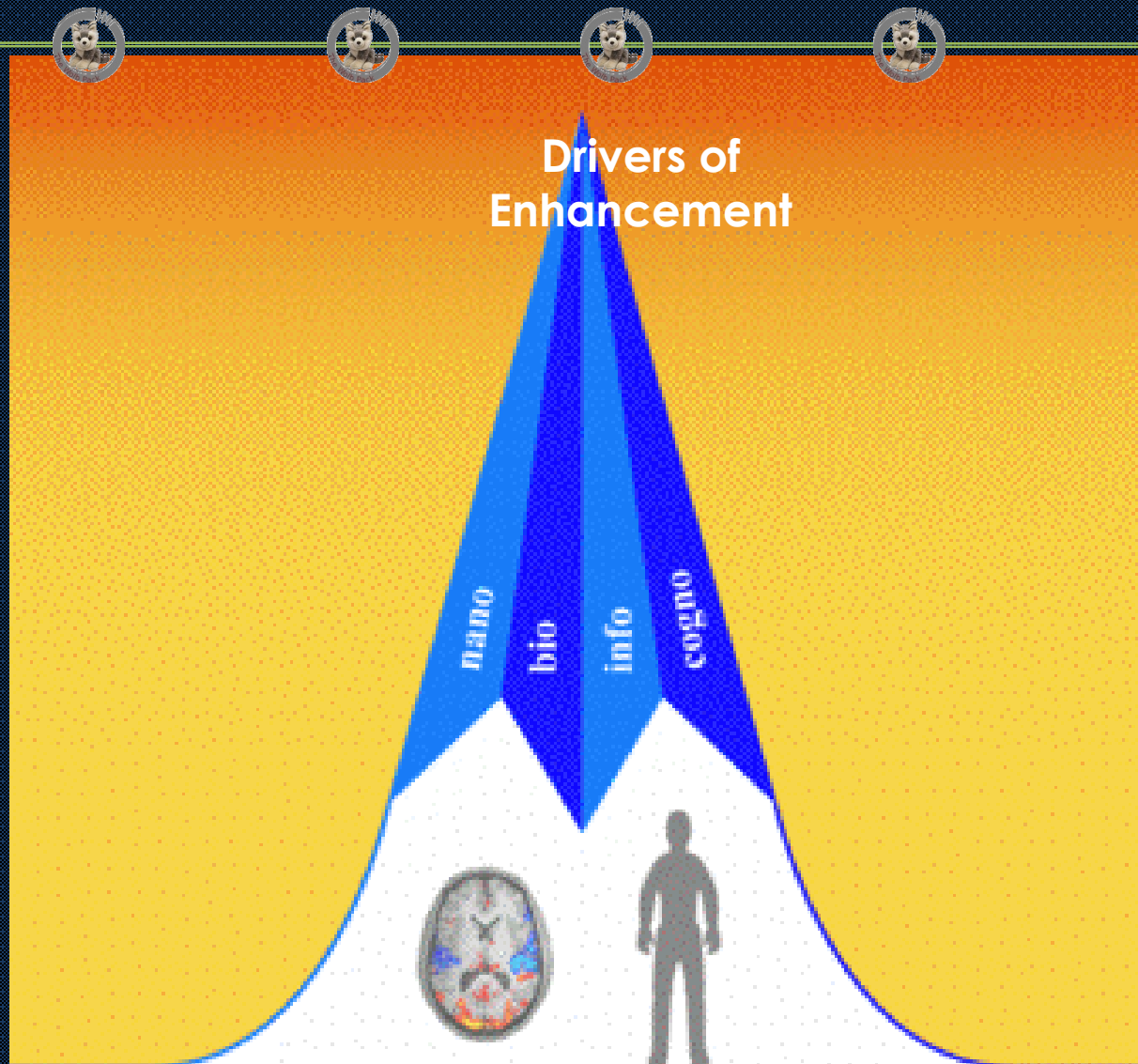
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Drivers of
Enhancement

Perception

Keyword	Google Scholar	Google
"Genetic risk" "Down Syndrome"	1,490	46,300
"Genetic probability" "Down Syndrome"	2	28
risk "Down Syndrome"	22,600	1,790,000
Probability "Down Syndrome"	5210	162,000

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Converging Technologies for Improving Human Performance:
Nanotechnology, Biotechnology, Information Technology and Cognitive Science (NBIC)



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Drivers of
Enhancement

The NBIC report used the term **productivity** over 60 times and the term **efficiency** 54 times and the term **competitiveness** 29 times.

Coenen Schuijff, Smits, Klaassen, Hennen, Rader and Wolbring (2009) Human Enhancement Study for European Parliament; Directorate General for internal policies, Policy Dept. A: Economic and Scientific Policy Science and Technology Options Assessments. This project was carried out by the Institute for Technology Assessment and Systems Analysis (ITAS), Research Centre Karlsruhe, and the Rathenau Institute, as members of the European Technology Assessment Group (ETAG).



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Drivers of Enhancement

- 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)



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Drivers of Enhancement

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- 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/sfrr/projects/human_enhancement



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Drivers of Enhancement

“I think it's irresponsible not to try and direct evolution to produce a human being who will be an asset to the world.”

“My view is that, despite the risks, we should give serious consideration to germ-line gene therapy. I only hope that the many biologists who share my opinion will stand tall in the debates to come and not be intimidated by the inevitable criticism ... If such work be called eugenics, then I am a eugenicist.”

“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



Hoppe B, Dugan D (Producers). (2003). DNA [Videotape]. United States: Windfall Productions Inc.
Watson, James D. (2004). *DNA*. New York, NY: Alfred Knopf.
Image:

http://nobelprize.org/nobel_prizes/medicine/laureates/1962/watson-bio.html



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Drivers of
Enhancement

and some ethicists talk about the obligation to enhance oneself beyond the species-typical

- Harris, J. *Enhancing Evolution The Ethical Case for Making Better People*; Princeton University Press: 2007.
- Savulescu, J. *New breeds of humans: The moral obligation to enhance*. *Reproductive Biomedicine Online* 2005, 10, 36-39.



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Drivers of Enhancement

Role of Disabled People

- 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.**
- Carol Poore | Recovering Disability Rights in Weimar Germany *Radical History Review* Issue 94 (Winter 2006): 38–58 <http://rhr.dukejournals.org/cgi/reprint/2006/94/38.pdf>



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Drivers of Enhancement

- *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*).
- .



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Drivers of Enhancement

Role of Disabled People

- 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.



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Drivers of Enhancement

Role of Disabled People

- 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).



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Governance

Governance/Anticipatory governance of S&T



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Governance

Your role

- **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.**

Guston, D., The Anticipatory Governance of Emerging Technologies. *Journal of Korean Vacuum Society* **2010**, 19 (6), 432-441.

Wender, B. A.; Foley, R. W.; Guston, D. H.; Seager, T. P.; Wiek, A., Anticipatory Governance and Anticipatory Life Cycle Assessment of Single Wall Carbon Nanotube Anode Lithium ion Batteries. *Nanotechnology Law & Business* **2012**, 9 (3), 201-216.



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Governance

- Question: Which ability expectations drive a given S&T and its governance?

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Is Social Science Research in the National Interest?

A battle is raging in the House of Representatives over an effort to clip the National Science Foundation's wings

May 21, 2014 | By Rep. Lamar Smith, Peter McPherson and Hunter Rawlings

Today the science committee of the U.S. House of Representatives will begin debate on a bill key to national research funding and priorities. The Frontiers in Innovation, Research, Science and Technology (FIRST) Act of 2014 (H.R. 4186) would, among other things, require the National Science Foundation to cut research for social sciences and economics and certify to Congress that each taxpayer-funded grant it issues is in the national interest.

Last week *Scientific American* published an interview with Neal Lane, a former White House science advisor, that was critical of the FIRST Act. Rep. Lamar Smith (R-Texas), chair of the House Science, Space and Technology Committee and co-sponsor of the FIRST Act, contacted us and asked for a chance to respond. We publish Rep. Smith's essay below along with a commentary on the FIRST Act by Hunter Rawlings, president of the Association of American Universities, and Peter McPherson, president of the Association of Public and Land-grant Universities.—*The Editors*



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Governance

Role of

Governance/ Anticipatory governance assume many abilities of the stakeholders

Keywords	Google Scholar
Occupational Therapy	336,000
+Technology governance/governance of technology	22/1 none relevant
Physical therapy	868,000
+Technology governance/governance of technology	15/0 none relevant
rehabilitation engineering	34600
+Technology governance/governance of technology	6/2 none relevant



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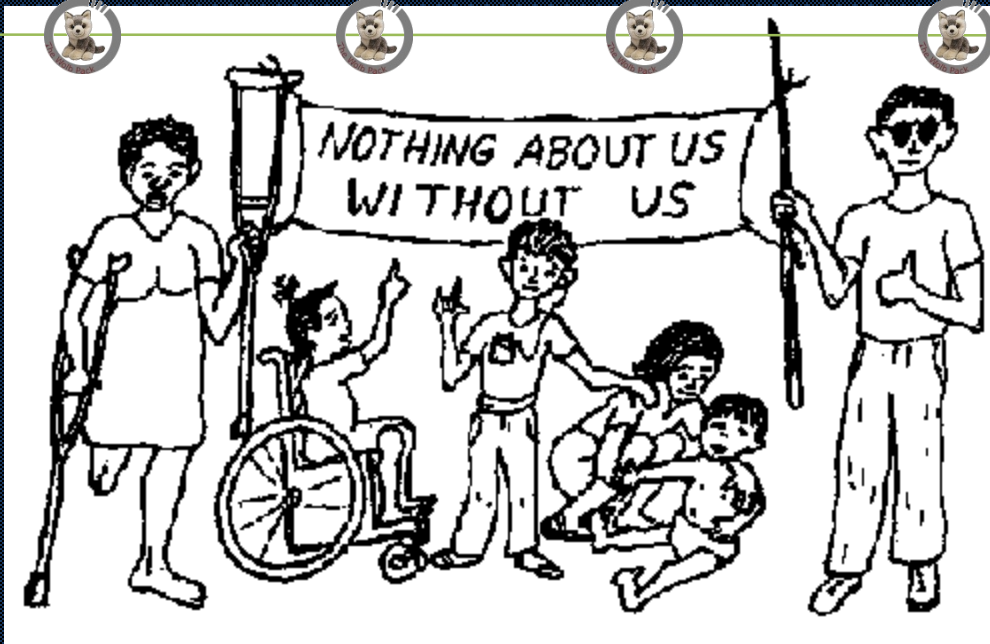
Governance

Your role

- **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





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Conclusion

Your turn
Any questions?

