

# **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,  
Indianapolis, USA, June 14,  
2014**

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# **"Healthy", "Disabled": What Do These Terms Mean?**

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# **Governance of Science and Technology through an Ability Studies Lens**

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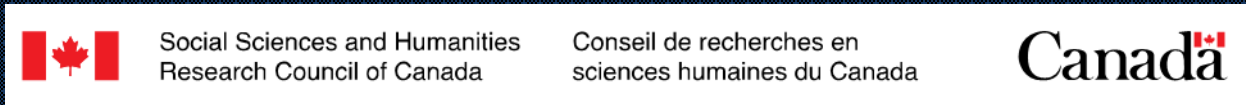
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# My Students The Wolb Pack

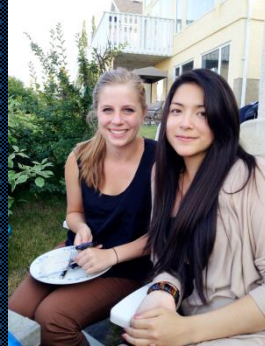
A Collaborative Interdisciplinary Student Research Team

[http://www.crd.s.org/research/faculty/Gregor\\_Wolbring.s.html](http://www.crd.s.org/research/faculty/Gregor_Wolbring.s.html)





## The Pack



## 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 Choii  
 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 Wolb-Pack: A Collaborative Interdisciplinary Student Research Team

Gregor Wolbring ([gwolbrin@ucalgary.ca](mailto:gwolbrin@ucalgary.ca)) and Jesse Hendrikse ([jhendri@ucalgary.ca](mailto:jhendri@ucalgary.ca))

Boushra Abdullab, Natalie Ball, Jennifer Cheung, Lucy Diep, Emily Hutcheon, Verlyn Leopatra, Brian Litke, Rachel Mackay, Angelica Martin, Kalie Mosig, Jacqueline Noga, Sonum Panesar, Theresa Rybchinski, Eniola Salami, Kazi Shave, Jeremy Tyndal, and Sophya Yumakulov

## • WHO WE ARE

- Group of graduate and undergraduate (1<sup>st</sup>-4<sup>th</sup> year) students pursuing different degrees, supervised by Gregor Wolbring
- Students and their supervisors (Jesse Hendrikse)
- Students joining independently of their supervisors
- Our academic work reflects diverse personal research interests: e.g. social robotics, sports, sustainability, and neuroenhancements
- Many of our academic projects are grounded in the framework of ableism and disability studies
- We employ a variety of methodologies (qualitative, quantitative and mixed methods)
- We communicate our research virtually and non-virtually through posters, papers, and oral presentations



## • WHAT WE DO

- Share ideas
- Collaborate with and learn from each other
- Help integrate new students into the world of research
- Support future academic and non-academic endeavours



## • INSPIRE (International Network of Student Perspectives In Research)

- In 2012, we co-founded the 1<sup>st</sup> INSPIRE Symposium (an online symposium for students to share their research and collaborate with one another)
  - 23 student presenters from: Canada, China, Belgium, UK, and USA
- The 2<sup>nd</sup> annual symposium will take place in fall 2013



*"The Wolb-Pack relies on each other for so much more than academic mentorship, and that is what makes it so easy to depend on the team for help, both in my academic and personal life."*

- Jacqueline Noga

*"The Wolb-Pack has been an incredible resource particularly with regards to feedback as I continue to disseminate my graduate work. And I have swapped great recipes and received expert knitting lessons! In a word: unbeatable."*

- Emily Hutcheon

*"It is an absolute pleasure to be a member of the Wolb-Pack! To learn, to share my own knowledge, and to help other students navigate the world of research. The support we offer and the relationships we cultivate have enriched my university experience beyond measure and I hope to continue to be a part of it!"*

- Sophya Yumakulov

*"We joined The Wolb-Pack because we believe that collaboration is an important skill for our academic career and in developing our interpersonal skills. Having peer support available has provided a sense of group effort and teamwork. We also feel we have a great mentor in Gregor Wolbring."*

- Boushra Abdullab, Jennifer Cheung, Rachel Mackay, and Sonum Panesar



## • HOW WE WORK

- Meet weekly as a group throughout the year (and many of us work together in the same physical space Mo-Fri (May-Sept).
- Individual members meet with their PI (principal investigator) weekly
- Provide mutual support as mentors and mentees
- Share our research and academic expertise with each other
- Provide constructive advice and feedback to each other's work
- Look for opportunities to co-author academic papers for peer reviewed journals, and abstracts for conferences
- Stay in contact with alumni through listserv
- Use our logo in our presentations and posters (designed by team member, Verlyn Leopatra) to highlight the support of our group

## • ACTIVITIES OUTSIDE THE WORK PLACE

- We are colleagues who have become friends
- Our less formal relationship has allowed us to form a strong team through:
  - Potlucks, knitting, peer support, including gift baskets and moral support

## • GROUP AND INDIVIDUAL OUTPUT

- To find out more about the group and its output please visit: [http://www.crd.s.org/research/faculty/Gregor\\_Wolbring.shtml](http://www.crd.s.org/research/faculty/Gregor_Wolbring.shtml)



## The Pack

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



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
- As used within the disability rights movement and disability studies it questions the expectation of 'species -typical body-linked abilities' while labelling 'sub species-typical abilities' as deficient, as impaired and undesirable often with the accompanying disablism (Miller, Parker, and Gillinson 2004), the lack of accommodation enthusiasm for the needs of people and other biological structures who are seen to not have certain abilities; the unwillingness to adapt to the needs of 'others'
- 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.



## The Pack **Ability Studies**

- Ableism is one of the most societal entrenched and accepted isms and one of the biggest enabler for other isms
  - Sexism
  - Racism/Ethnicism/
  - Caste-ism
  - Age-ism
- Ableism driven Speciesism
- Ableism driven Anti-Environmentalism Anthropocentric versus Biocentric; Ecuador first Biocracy
- Gross domestic product (GDP)-ism
- Consumerism
- Productivity-ism
- Competitiveness-ism

Wolbring (2010) Nanoscale science and technology and social cohesion for International Journal of Nanotechnology Int. J. Nanotechnol., Vol. 7, Nos. 2/3, 2010 pp 155-173



## The Pack **Ability Studies**

- Ability Studies allows to investigate eco-ability expectations and eco-ableism that focuses on ecological dynamics of human-human; human-animal and human-environment relationships.
- Ability Studies allows for the study of multiple subject formations, social relationships, and lived experiences based on diverse ability expectations and the actions linked to such expectations.
- It encourages the study of how legal, ethical/moral, biological, cultural and social constructs are exhibiting ability expectations and how such ability expectations and the actions they trigger leads to an ability based and ability justified understanding of oneself, one's body and one's relationship with others of one's species, other species and one's environment.
- It allows for the investigation of ability expectations exhibited not only by individuals but also by countries and cultures
- It allows for the investigation of which ability expectation can positively reinforce another ability expectation; which are in conflict with each other and which are neutral to each other
- Ability studies can be used in inter-, trans- and intra- disciplinarily ways to generate policies and advance the relationship between humans, animals and their environment.



The Pack

Ability Studies

**Ethics and Ability  
expectations**

- Ethics codes, theories and principles are intended to help society to deal with emerging issues such as the governance of scientific and technological advancements.
- They are linked intricately to abilities needed to make a given ethics code, theory or principles operational
- A given ethics theory, code or principle privileges certain abilities and as such its uptake correlates with the privileging certain ability expectations.
- Privileging certain ability expectations were and are one trigger for the development of ethics theories, codes and principles;



The Pack

S&T

- 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

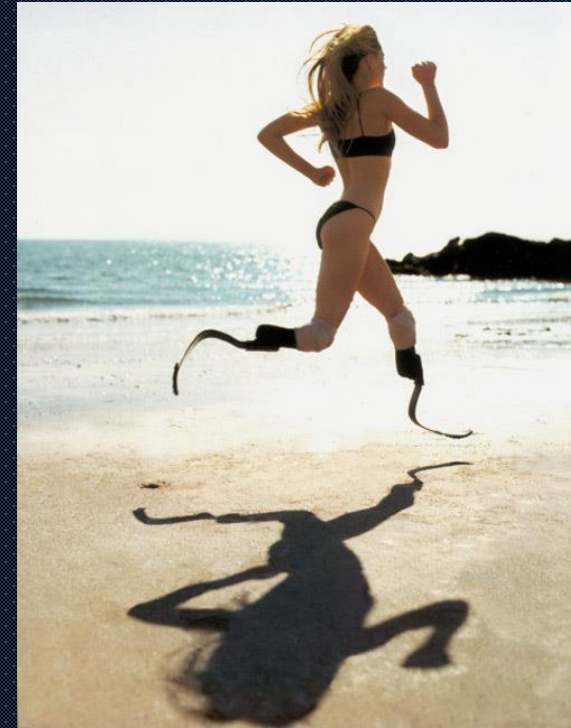
S&T





# The Pack

# S&T

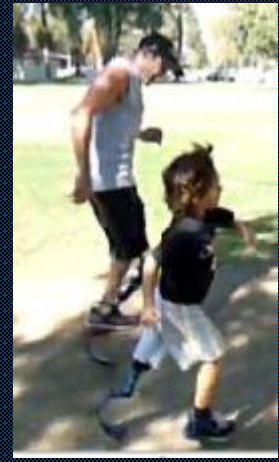


© ANDY HOOPER



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





The Pack

S&T



**FIG. 3**  
Robotic assistance for elderly or infirm people, or those with disabilities

**Backpack**  
Contains a computer with a wireless network connection

**Battery**

**Actuators**  
Electric motors provide powered-assisted movement to the limbs

**Angular sensor**  
Detects the angle of the hip, knee and ankle joints

**Bioelectric sensors**  
Sensors attached to the skin monitor nerve impulses from the brain to the muscles indicating that a movement like standing or walking is about to take place. The signal is relayed to the computer, where it is analysed and used to launch the actuators even before the suit's wearer moves

**Floor reaction force sensor**  
Detects the user's centre of gravity



PHOTO: SARCOS/STANLEY HARRIS

[www.youtube.com/watch?v=IYWd2C3XVIk](http://www.youtube.com/watch?v=IYWd2C3XVIk)  
<http://www.sarcos.com/>



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S&T



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



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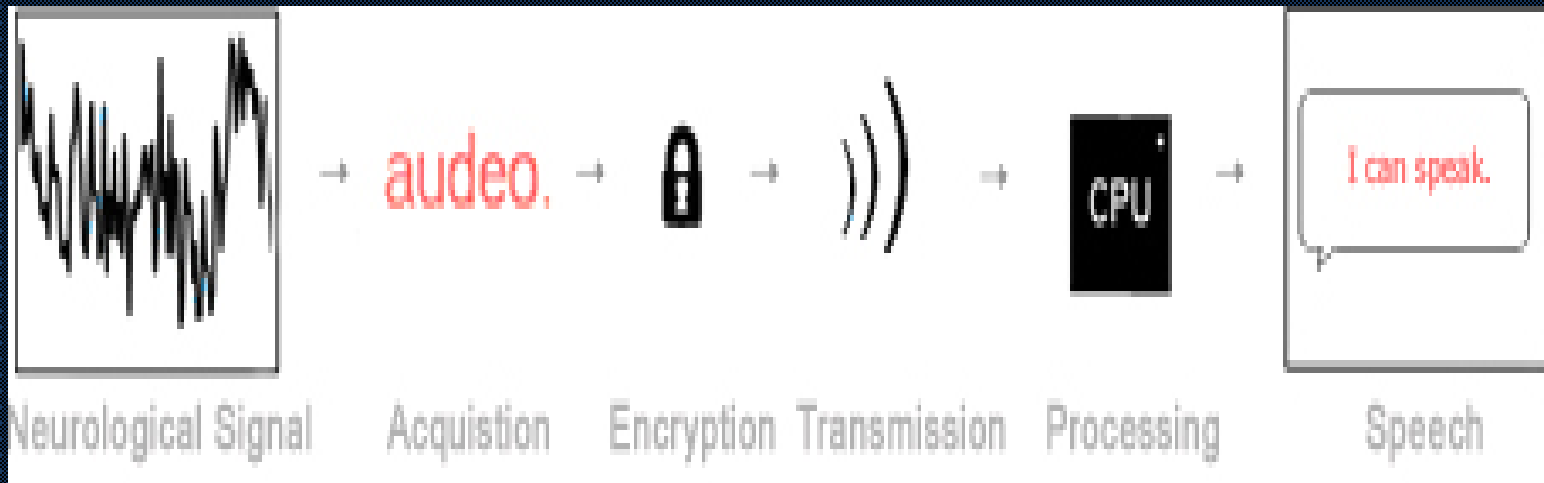




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S&T

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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S&T



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.

**Neurotransmitter sensor**; application mental health issue

**Galvanic Skin Sensor**; application: measures stress levels through electrical conductivity of skin

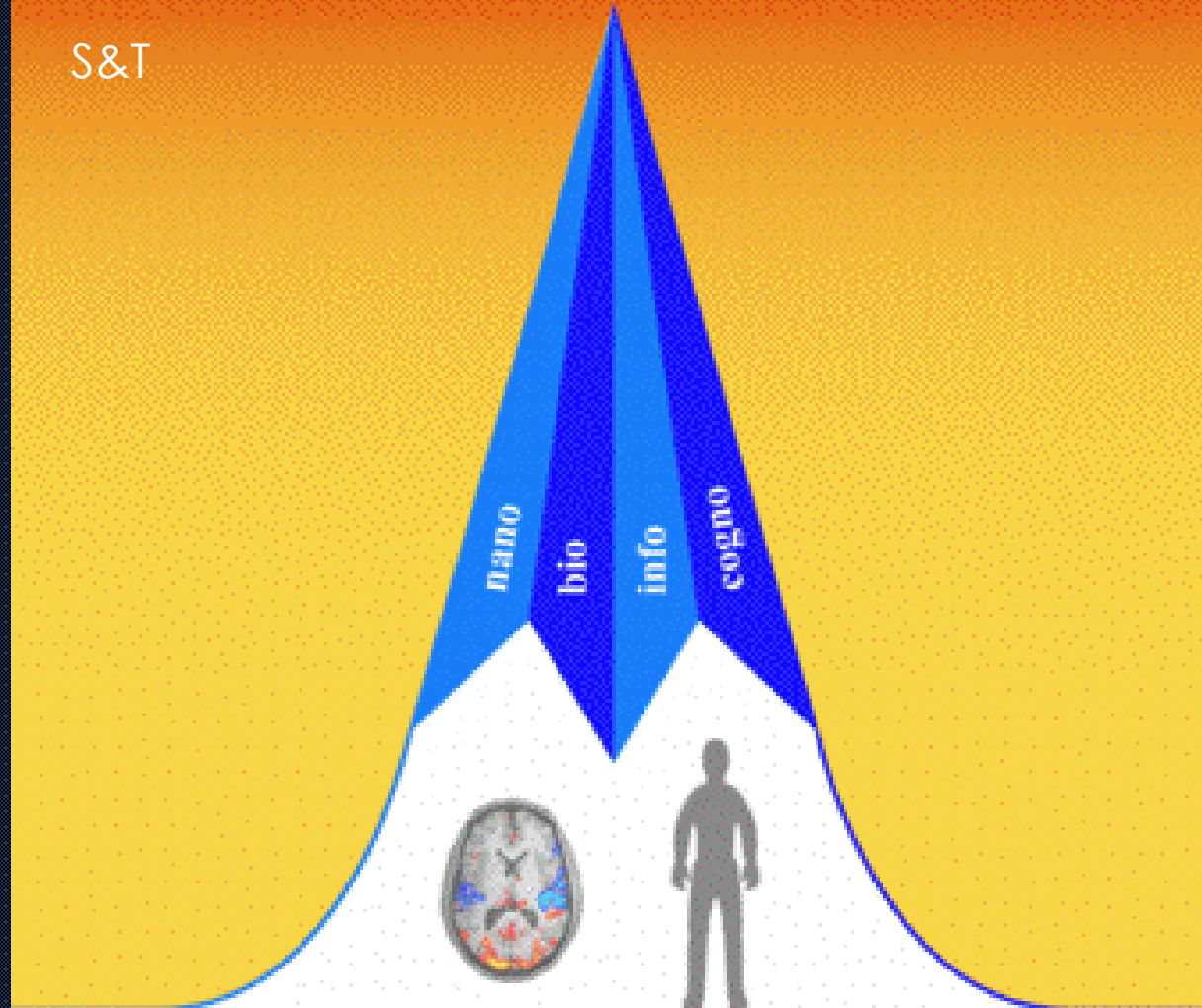
Automatic drug delivery systems; application: for example insulin pumps and pain medications

Wireless wearable health statistic generating devices, example; heart rate watches, Jawbone Up Bracelet; application: to monitor and track common biostats such as blood pressure, heart rate, sleep cycles, nutrients, biomarkers etc.



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S&T

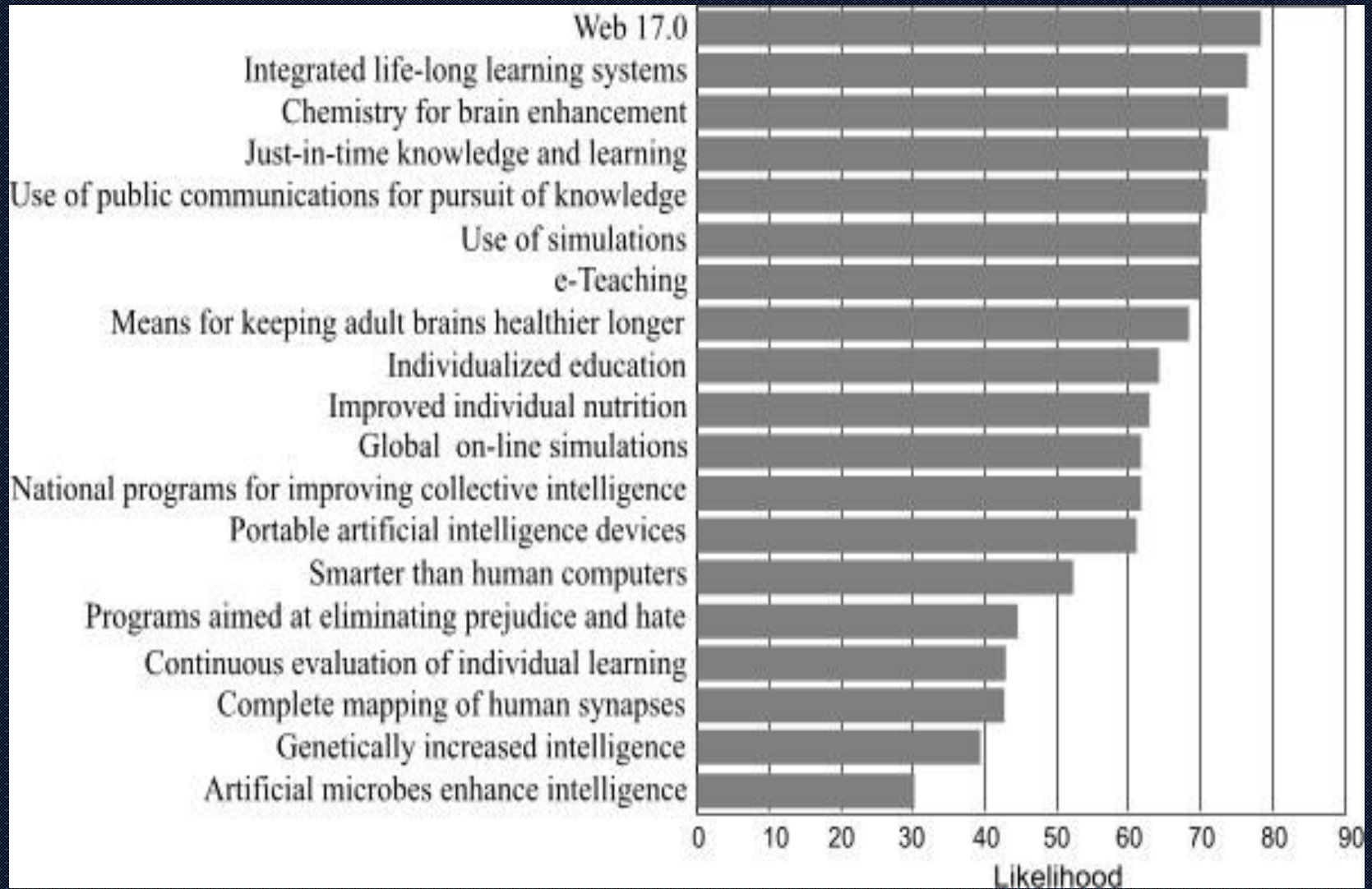


Converging Technologies for Improving Human Performance:  
Nanotechnology, Biotechnology, Information Technology and Cognitive Science (NBIC)



The Pack

S&T





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S&T

**The holy grail?**



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S&T

## 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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S&T

- 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

The Pack

S&T





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**Eugenics**



Ableism



Conclusion

- Positive eugenics is aimed at increasing the number of desired phenotypic and genotypic traits within the population (Fisher, 1917). Traditionally, positive eugenics was achieved by encouraging those with desirable traits to reproduce with one another. In the future, positive eugenics might be achieved through the synthesis of the desired genome from scratch (synthetic biology) in combination with the artificial womb. Because many genes are impacted by environmental factors, elimination of environmental factors that impact genes negatively also can be seen as fitting with the aim of positive eugenics. Ref see

[http://www.ijdcrc.ca/VOL12\\_02/articles/ball.shtml](http://www.ijdcrc.ca/VOL12_02/articles/ball.shtml)



The Pack

Meaning  
of ....

**Meaning of...**



The Pack

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**.



The Pack

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



The Pack

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,'



The Pack

Meaning  
of DALY

- DALY is a health gap measure developed with the intent to give guidance for allocating medical health treatment dollars (Murray CJL et al. 2002), to "curtail allocative inefficiency" (Murray and Acharya 1997:703-730). Murray states, "...individuals prefer, after appropriate deliberation, to extend the life of healthy individuals rather than those in a health state worse than perfect health" (Murray and Acharya 1997:703-730).



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Meaning  
of DALY

- If we apply this notion to a transhumanized model of health that quote would say,
- “ individuals prefer, after appropriate deliberation, to ENHANCE the life of healthy individuals rather than treat those in a health state worse than perfect health.”
- This position could be used to justify favoring ‘enhancement medicine’ over ‘curative medicine’ seeing pure curative medicine to the species typical state as futile and waste of health care dollars.



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Meaning  
of ...

Enhancement model of  
Health Insurance business  
Right to Health  
Burden of disease  
Impairment



The Pack

Drivers of  
Enhancement

**What drives the move toward a enhancement vision?**



The Pack

Drivers of  
Enhancement

Perception

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



## The Pack

## Drivers of Enhancement

### Keyword

### Google

#### Portuguese

"Sindrome de down"	"risco genético"	229
"Sindrome de down"	"probabilidade genética"	4
"Sindrome de down"	"risco"	127000
"Sindrome de down"	"probabilidade"	20800

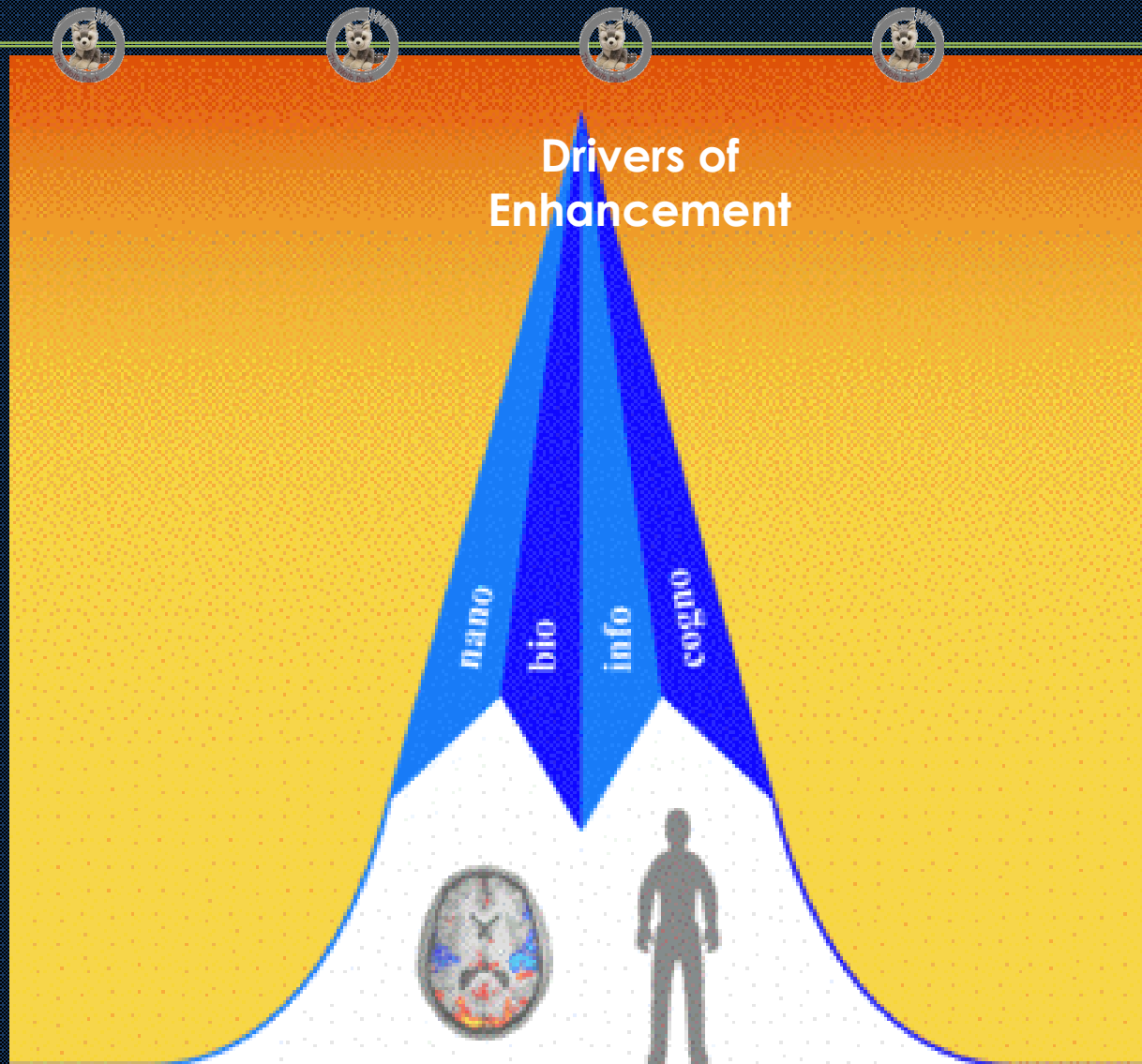
#### Spanish

"Sindrome de down"	"riesgo genético"	440
"Sindrome de down"	"probabilidad genética"	0
"Sindrome de down"	"riesgo"	219000
"Sindrome de down"	"probabilidad"	49000

#### German

"Genetisches Risiko"	"Down Syndrom"	15000
"Genetische Wahrscheinlichkeit"	"Down Syndrom"	0
"Risiko"	"Down Syndrom"	122100

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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

- ,
- polls indicate that personal interest in or aversion to using Human enhancement technologies depends on one's perceived social status, and how Human enhancement would affect his/her competitive advantage.
- Canton has identified several market pressures leading to rapid development of HE technologies:
  - 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](http://www.aaas.org/spp/sfrl/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](http://nobelprize.org/nobel_prizes/medicine/laureates/1962/watson-bio.html)



The Pack

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.



The Pack

## 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>



## The Pack

## Drivers of Enhancement

- *Donovan, Egger, Kapernick and Mendoza investigated in 2002 what might generate a climate of achieving Performance Enhancing Drug Compliance in Sport (Donovan, Egger, Kapernick, & Mendoza, 2002).*
- 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 et al., 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 (Denison Jayasooria, 1999; Jenny Morris, 2005; Rapp & Ginsburg, 2001; Barton, 1993; Meekosha & Dowse, 1997).
- 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).
- If disabled people are indeed not accepted, respected and accommodated for who they are, if this option is taken off the table and if the disabled person believes that he/she only receives respect and access to society by employing body technologies to modify oneself it seems nearly impossible for disabled persons to stay with their as 'obsolescent' as defective labelled body.



The Pack

Governance

# Governance of S&T through an Ability Studies lens:



The Pack

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 [52-53].**

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.



## The Pack

## Governance

- **Question: What is the impact of a given S&T on Ability inequality and Ability InEquity?**
- **Ability inequality is a descriptive term denoting any uneven distribution of access to and protection from abilities generated through human interventions, right or wrong (modified from Cozzens ).**
- *Ability inequality* is a descriptive term denoting any uneven judgment of abilities intrinsic to biological structures such as the human body, right or wrong modified from Cozzens ).
- *Ability inequity* is a normative term denoting an unjust or unfair distribution of access to and protection from abilities generated through human interventions (modified from Cozzens).
- *Ability inequity* is a normative term denoting an unjust or unfair judgment of abilities intrinsic to biological structures such as the human body (modified from Cozzens).



## The Pack

## Governance

- Question: What is the impact of any given S&T on Ability Security?
- Ability security means that one is able to live a decent life with whatever set of abilities one has, and that one will not be forced to have a prescribed set of abilities to live a secure life (e.g. even if one doesn't have the ability to walk, he or she should be able to secure employment).
- 
- Example: According to the US bureau of labor statistics January 2014 the employment to population ratio for disabled people age 16-64 years is 25.5% for men with disabilities and 22.8% for women with disabilities These numbers included people who look for work but cannot find work and people who do not look for work. The equivalent numbers for so called non-impaired people are 75.3% for men with disabilities and 65.7% for women
- <http://www.bls.gov/news.release/empsit.t06.htm>



## The Pack

## Governance

- **Question: What is the impact of a given S&T on Self-Identity security?**
- Self-identity security could be seen as a subset of personal security and means that one is accepted with one's set of abilities and that one should not be forced (physically or by circumstance) to accept a perception of oneself one does not agree with (e.g. one is not expected to have the ability to walk or is seen as a "deficient product" if one cannot walk).
- **If we for example look at the academic literature of social robotics or brain machine/brain computer interfaces the language is nearly exclusive following a medical understanding of disabled people and the purpose of restoration.**

**The narrative is not indicating the ability expectation of decreasing the social discrimination ability diverse people experience**



The Pack

**Governance**

- Question: Which ability expectations drive a given S&T
- A 2006 Association for the Advancement of Science workshop looked into the dynamic of human enhancement and concluded that the following ability desires are the main drivers for human enhancements: 1) to keep one's local and global competitive advantage; 2) to live securely; and 3) to maintain one's quality of life and one's consumer life-style.



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Governance

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

The screenshot shows the top navigation bar of the Scientific American website. On the left is the logo 'SCIENTIFIC AMERICAN™'. To its right are links for 'Sign In | Register' and a search bar with the text 'Search ScientificAmerican.com'. Further right is a 'Subscription Center' with links for 'Subscribe to All Access', 'Subscribe to Print', 'Give a Gift', and 'View the Latest Issue'. Below this is a horizontal menu with categories: 'Subscribe', 'News & Features', 'Topics', 'Blogs', 'Videos & Podcasts', 'Education', 'Citizen Science', 'SA Magazine', 'SA Mind', and 'Books'. The main article section features the title 'Is Social Science Research in the National Interest?' in a large, bold font. Below the title is a sub-headline: 'A battle is raging in the House of Representatives over an effort to clip the National Science Foundation's wings'. The byline reads 'May 21, 2014 | By Rep. Lamar Smith, Peter McPherson and Hunter Rawlings'. The first paragraph of the article begins: '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.' The second paragraph starts: '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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- Question what ability expectation does S&T support?
- Democratizing Nano versus Nano for furthering democracy
- To better connect science and democracy, there must be a way for society to guide the developments of science. Pirtle 2006
- To better allow for democracy to decide what good science should achieve, a serious and proactive
- assessment of the possible implications of scientific work is needed in order to make informed, democratic
- decisions (2). Pirtle 2006
- “The first focus of converging technologies should be on the benefits to individuals and society in general. Good indicators of success are the quality of life, health, safety, and how humanely and democratically the benefits are distributed. Application of democratic principles for equal opportunity, access to information, knowledge and development are other challenges. This report is based on scientific evidence and underlines the need to respect the human condition, democracy, and serving human needs. Optimizing societal interactions, R&D policies and risk governance for the converging new technologies can enhance economic competitiveness and democratization.” (Roco 2008)



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- Question:
- Which S&T products have been influential so far in supporting abilities seen as essential for Democracy?
- Which S&T products could be influential in supporting abilities seen as essential for Democracy?
- Which S&T products have been detrimental so far in regards to abilities seen as essential for Democracy?
- Which S&T products could be detrimental in regards to abilities seen as essential for Democracy?



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- Does a given S&T product decrease, increase or maintain existing levels of Ability privileges?
- Does a given S&T generate new Ability Privileges? If Yes for whom?



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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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## Role of Social Work

- Governance/ Anticipatory governance assume many abilities of the stakeholders

Keywords	EBSCO (all)(abstract)	Scopus (title, abstract, keyword)	Science direct (title, abstract, keyword)	Web of Science (topic)	Google Scholar
Social work	156,908	33786	871	17422	1,480,000
+”social robot	0	0	0	0	27/5 relevant
+brain machine interface	0	0	0	0	12/0 relevant
+brain computer interface	1	0	0	0	55/1 relevant
+human enhancement	0	0	0	0	0 relevant
+Neuro/cognitive enhancement	0/3	0/7	0/0	0/2	27(0relevant) /
+Technology governance/governan ce of technology	0/0	0/0	0/0	0/0	91/6 but none relevant



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## Role of Social Work

- Vision of purpose of social work education
- facilitating the transaction between individuals and their environments for purposes of problem solving (Parsons, 1991)
- empowerment (Parsons, 1991)
- to promote recovery, restore individual, family and community well-being, enhance development of each individual's power and control over his or her life and advance principles of social justice (McGarry, 2014)
- addressing need in the light of people's lived experience (Cox, 2002);
- "to advocate for, and/or with people changes in those policies and structural conditions that maintain people in marginalized dispossessed and vulnerable positions" (Rock, 2013) ;
- to enhance people's well-being (Knauth, 2014);
- to increase betterment of living conditions of a client, a family, or a community (Soydan, 2011);
- Understand the mechanisms of oppression and discrimination. (Qatar University Social work program, 2014)
- Apply strategies of advocacy and social change to advance social justice (Qatar University Social work program, 2014) .



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- Sherwin recently stated, “we [ethicists] lack the appropriate intellectual tools for promoting deep moral change in our society” (Sherwin, S. LOOKING BACKWARDS, LOOKING FORWARD: HOPES FOR BIOETHICS'NEXT TWENTYGÇÉFIVE YEARS. Bioethics 2011, 25 (2), 75-82).



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- However question is who is the 'we' in Sherwin's quote? Do all ethicists have the same problem of lack of influence?
- I submit that understanding ability expectation dynamics/ability privileging dynamic is essential for understanding how to make a real difference.
- Ethical reasoning and the use of ethics theories per se does not lead people or institutions to change. Change in ability expectations/change in ability privileging are the levers of social and political change;
- I proposed in 2008 the area of Ableism Ethics.



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Role of Academics

- In this consultation the following roles were envisioned for academics and academic institutions (we use quotes here so people who want to find the original comments can search the consultation document for a quote to, for example, identify the author of a given quote; we find this important given that the open access feature of the journal allows non-academic disabled people to access the article who might be interested in certain comments and want to find these comments without reading the whole consultation) .



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## Role of Academics

- “Work closely with all other stakeholders in the area and undertake research which can provide an evidence base for addressing relevant policy and practice challenges”;
- “should undertake research on relevant topics to increase knowledge and understanding of the CRPD and the human rights-based approach to disability, and to develop tools for development programming and planning”; “monitor CRPD”;
- “provide evidence for effective inclusive practices in development/research”; “include disability as a topic in relevant study courses”;
- “develop, organize and monitor specific study courses e.g. for rehabilitation professionals and inclusive education”;
- “to research, publish and interrogate reliable data on disability and ensure that it is disseminated to inform policy and programmes and the appropriate levels”;



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## Role of Academics

- “to conduct action research to highlight and develop efficient tools and methods to accelerate disability-inclusive policies and practices”.
- “to harmonize efforts towards improved data collection methods and systems”;
- “teach universal design”;
- “capacity building and awareness-raising throughout society”
- “encourage awareness and disability studies at schools, universities and other educational institutions”; “support students with disabilities”;
- “push for disability inclusive educational institutions”.
- As to academic institutions the following was proposed:
- “Become disability inclusive institutions so all students can access sources of education”;



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## Role of Academics

- “provide disability awareness in all curricula”;
- “support research on disability”;
- “ensure that all data is disaggregated by disability, ethnicity, age, and gender”;
- “conduct research to sharpen the tools of inclusive development”;
- “create knowledge base on inclusive development both in policy and practice”;
- “contribute to data collection methods and systems”;
- “research to enhance the access of persons with visual disabilities to affordable assistive devices and technology”;
- “in terms of ways forward, opportunities for enriched and fulfilling lives within disability”;



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## Role of Academics

- “inclusive pathways throughout the education system with effective support mechanisms and opportunities to excel”;
- “partnership programmes with the business, council and private sectors to develop inclusive communities”;
- “inclusive communities within the educational establishments themselves at all levels”. “Programmes to develop disabled leaders”;
- “make it real”;
- “research institutions should undertake research on issues of persons with disabilities”;
- “Research on technology and innovations designing products and services accessible for all”;
- “Training and sensitization on the rights of persons with disabilities across sectors”.



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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 as impaired perceived people?**
- **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

- Given Galton's understanding of eugenics, eugenic goals are not bound to the past, nor is it required that they only target those we labeled up to now as having deficiencies. Eugenic thinking can also be applied to enhance humans beyond the normal through, for example, somatic and germline genetic enhancement. The only prerequisite is that these interventions give an advantage to the beyond the normal enhanced over others and that this advantage is durable and benefits the stock in the end.
- Ref see [http://www.ijdcrc.ca/VOL12\\_02/articles/ball.shtml](http://www.ijdcrc.ca/VOL12_02/articles/ball.shtml)



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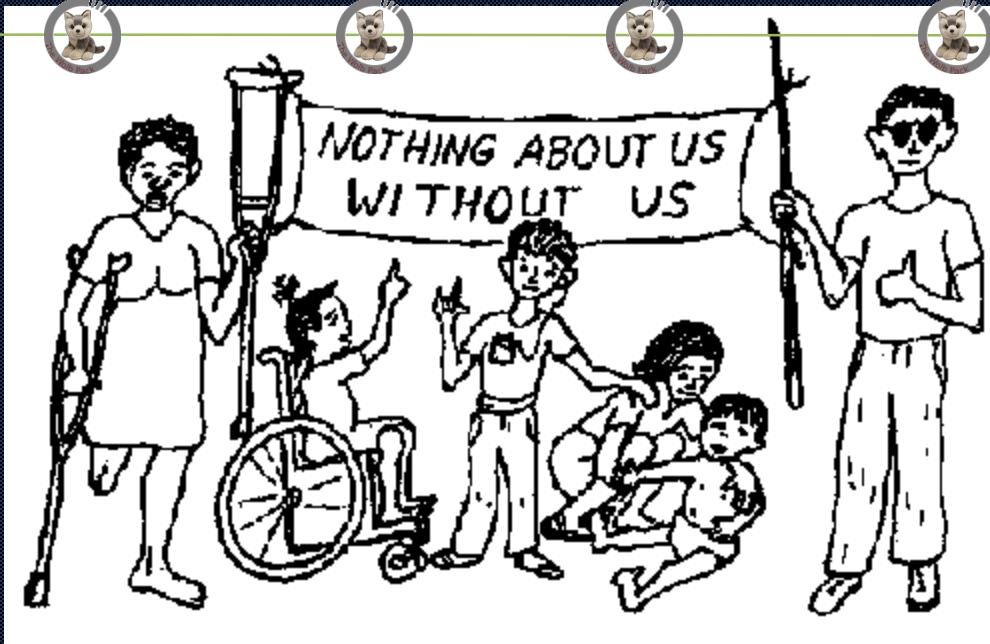
## Conclusion

- **Conversation between Alex D and Paul Denton**
- **Paul Denton:** If you want to even out the social order, you have to change the nature of power itself. Right? And what creates power? Wealth, physical strength, legislation — maybe — but none of those is the root principle of power.
- **Alex D:** I'm listening.
- **Paul Denton:** Ability is the ideal that drives the modern state. It's a synonym for one's worth, one's social reach, one's "election," in the Biblical sense, and it's the ideal that needs to be changed if people are to begin living as equals.
- **Alex D:** And you think you can equalise humanity with biomodification?
- **Paul Denton:** The commodification of ability — tuition, of course, but, increasingly, genetic treatments, cybernetic protocols, now biomods — has had the side effect of creating a self-perpetuating aristocracy in all advanced societies. **When ability becomes a public resource, what will distinguish people will be what they do with it. Intention. Dedication. Integrity. The qualities we would choose as the bedrock of the social order. (*Deus Ex: Invisible War*)**

- Indeed 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).
- If disabled people are indeed not accepted, respected and accommodated for who they are, if this option is taken off the table and if the disabled person believes that he/she only receives respect and access to society by employing body technologies to modify oneself it seems nearly impossible for disabled persons to stay with their as 'obsolescent' as defective labelled body.



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# Conclusion





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Conclusion

Your turn  
Any questions?

