Scoping document on Nanotechnology and disabled people for the Center for Nanotechnology in Society at Arizona State University

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INTRODUCTION

The term 'nanotechnology' was used first to describe a way to manufacture something from atomic molecules (such as the food replicator in many science fiction films where one says, for example, "Coffee" and the machine builds, synthesizes the coffee molecule by molecule) (*1*).

However, due to sales pitch strategies by companies and others, the term nanotechnology has since then evolved into a different meaning. Today, nanotechnology is used to mean 'nanoscale technology' and nanoscale sciences covering 'nanotechnology' research and development products, ideas and processes with controlled size below 300nm. Many Nano-Taxonomies exist which show the numerous fields, processes and products covered under 'nanotechnology' today (*2*).

The original meaning of the term has been altered, and now 'nanotechnology' is generally known as molecular manufacturing or molecular nanotechnology (*2*).

Although the area of molecular manufacturing will have a huge impact on trade and related areas once it is operationalised, it will not be covered in this document.

This scoping paper takes into account that products and ideas for research and development are influenced by the convergence of nanotechnology with other technologies such as biotechnology, information technology and cognitive sciences (neuron engineering) and synthetic biology, which is described on the synthetic biology community webpage (http://syntheticbiology.org/) to mean:

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 (*3*).

In addition, I would add the reaction of other fields of sciences such as social sciences, medicine, economics, health technology assessment, health research, anthropology, environmental sciences, disability studies/variability studies towards these products and ideas for research and development.

Author's note: Although this document focuses on the impact of nanotechnology and NBICS on disabled people, the author believes that the line between who is disabled and who is not disabled is rather blurry (*4*) and that the so-called non-disabled are impacted by the situation/treatment of the disabled and vice versa.

BACKGROUND: NANOTECHNOLOGY / NBICS

Nanotechnology in all its meanings allows for, among other things, the manipulation of materials on an atomic or molecular scale and 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, including genetic engineering;
c. information technology, including advanced computing and communications;
d. cognitive science (neuro engineering)
e. synthetic biology.

Hence, the designation "NBICS" (nano-bio-info-cogno-synbio).

Many lists of anticipated Nanoproducts exist (*5;6*). The National Nanotechnology Initiative (US) envisions applications for NBIC products in areas such as the environment, energy, water, weapons and other military applications, globalization, agriculture, and health (e.g., more efficient diagnostics and genetic testing, cognitive enhancement; life extension and enhancing human performance in general) (*7*).

Others, such as transhumanists, believe that advances in NBICS hold the key for extreme life extension to the level of immortality and the achievement of morphological (*8*), "full reproductive,"(e.g., artificial womb research) (*9*), and genomic freedom (*10*). Another area that impacts and is impacted by nanotechnology includes synthetic biology (*11;12*).

The U.S. government spent nearly twice as much on nanotechnology in 2004 as it did on the Human Genome Project (HGP) in its peak year. Predictions are that expenditures in Nanotechnology will soon outstrip investments to date in Genomics and Biotechnology (*13*).

"By the end of 2005 governments had sunk eighteen billion dollars (US$18 billion) of taxpayers' money into nanotechnology R&D. With an additional six billion dollars (US$6 billion) forecast for 2006, nanotechnologies will then have received the same level of funding in absolute dollar terms as the entire Apollo program" (*14*). Many middle-income countries such as India (*15*), China (*16*) and others (*17*) are increasingly involved in nanotechnology. A Global R&D Report 'Changes in the R&D Community' by Battelle and published by R&D Magazine (*18*) puts China in 4th place behind India, Japan and the US in R&D spending (*19*).

(*18*)

Global R&D Spending					
	GDP PPP 2005 billions, $	R&D % GDP 2005 percent	R&D PPP 2005 billions, $	R&D PPP 2006 billions, $	R&D PPP 2007 billions, $
Americas	15,874	2.3	369.07	379.69	387.64
U.S.	12,192	2.6	319.60	328.90	335.50
Asia	19,086	1.8	341.30	361.85	384.01
China (Mainland)	8,859	1.4	124.03	136.30	149.80
Japan	3,890	3.2	124.48	127.84	131.29
India	3,611	1.0	36.11	38.85	41.81
Europe	12,764	1.8	236.09	240.16	244.42
Germany	2,388	2.5	59.68	60.21	60.75
France	1,879	2.2	41.36	42.10	42.86
UK	1,933	1.9	36.72	37.39	38.06
Other	2,276	1.4	31.88	33.76	35.68
World	50,002	2.0	978.34	1,015.46	1,051.75

Share of Total Global Research and Development			
	2005	2006	2007
Americas	37.7%	37.5%	36.8%
U.S.	32.7%	32.4%	31.9%
Asia	34.9%	35.6%	36.5%
China	12.7%	13.4%	14.8%
Japan	12.7%	12.6%	12.5%
India	3.7%	3.8%	4.0%
Europe	24.1%	23.6%	23.2%
Germany	6.1%	5.9%	5.8%
Other	3.3%	3.3%	3.5%
World	100.0%	100.0%	100.0%

Source: R&D Magazine, Battelle, OECD, World Bank

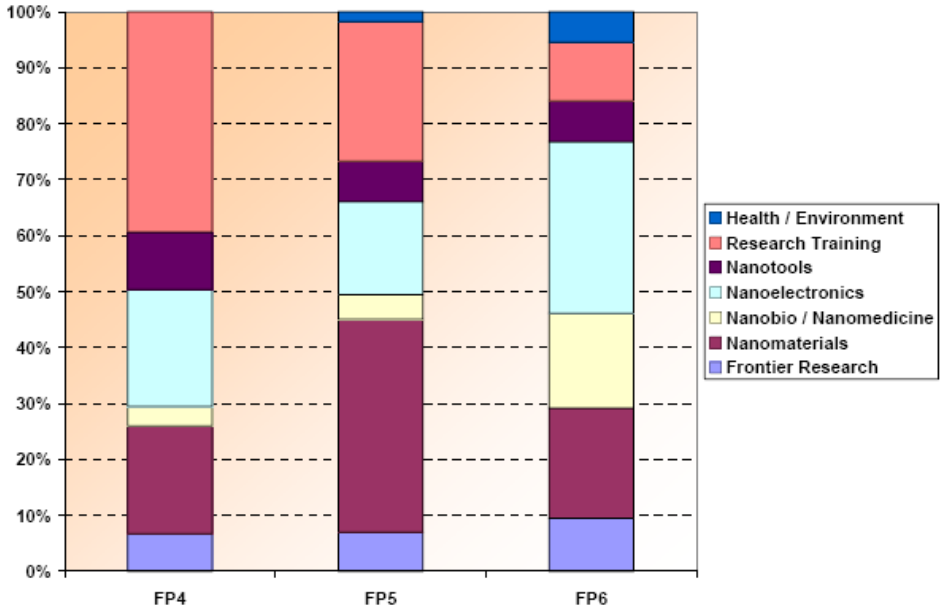
The 2006 Lux report (*20*) states the following:

Governments	Nanotechnology spending 2005
North America (nearly all Canada)	$1.7 billion (36%)
Asia (dominated by Japan)	$1.7 billion (36%)
Western Europe (led by Germany)	$1.1 billion (26%)
Rest of the World	$0.1 Billion (2.1%)

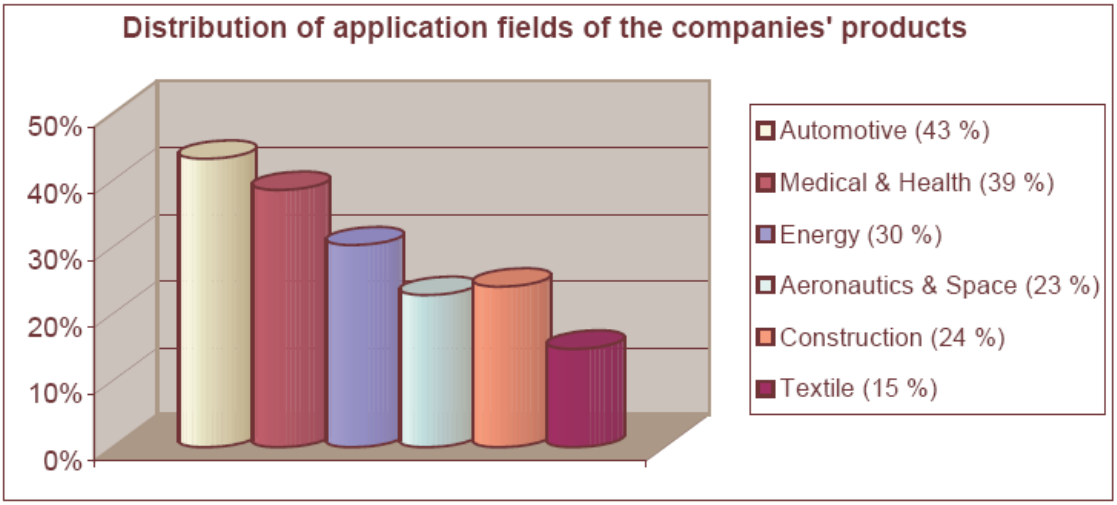
Established Corporations	Nanotechnology spending 2005
North America (nearly all Canada)	$1.9 billion (42%)
Asia (dominated by Japan)	$1.7 billion (38%)
Western Europe (led by Germany)	$0.85 billion (19%)
Rest of the World	$0.07 billion (2%)

The hierarchy in funding by Venture Capital stated by Lux is also reflected in the figures below of Nanotech R&D in Europe where Nanobio/Nanomedicine is second to Nano-electronics (*21*) and in the distribution of application fields of company products where automotives are number one but health and medicine are a close second (*22*).

Figure 17: Nanotechnology R&D areas supported by successive FPs



Electronics and IT deals lead with 40% of VC investment in 2004 and 2005, followed closely by life sciences with materials and nanotools as a distant third and fourth, respectively.



(*23*)

Nanobio is one of the biggest pieces in the pie--often the biggest--if one looks at Nano funding based on applications (*21;24;25*). Each of the fields of applications mentioned above come with their own sales pitches, social consequences, problems, and implications, and each deserve its own scoping paper.

This paper will focus on the area of Nano/NBICS medicine because this area is affecting disabled people the fastest and because many of its problems are not yet covered.

BACKGROUND: NANOMEDICINE/NBICS MEDICINE

Nanomedicine, by itself or in convergence with Bio-Info-Cogno-synbio sciences, is envisioned by some to have the answer to global problems of disease and ill health. Others argue for the pursuit of 'morphological freedom' (*8*)--allowing the human body to move beyond typical functioning of the species.

The nanomedicine glossary on the webpage 'Nanotechnology Now' describes nanomedicine as follows:

> (1) the comprehensive monitoring, control, construction, repair, defense, and improvement of all human biological systems, working from the molecular level, using engineered nanodevices and nanostructures; (2) the science and technology of diagnosing, treating, and preventing disease and traumatic injury, of relieving pain, and of preserving and improving human health, using molecular tools and molecular knowledge of the human body; (3) the employment of molecular machine systems to address medical problems, using molecular knowledge to maintain and improve human health at the molecular scale (*1*).

The journal *Nanomedicine: Nanotechnology, Biology and Medicine* was launched in March 2005 (*26*). Quite a few Nanomedicine Roadmaps also exist by now (*27*). According to Frost and Sullivann, nanotechnological processes in medicine will obtain a sales volume of about $180 billion until 2015 (*28*). According to the Freedonia group, "demand for nanotechnology health care products in the US is projected to increase nearly 50 per cent per year to $6.5 billion in 2009 and by 2020, demand for nanotechnology health care products is projected to exceed $100 billion" (*29*).

US NANOTECHNOLOGY HEALTH CARE PRODUCTS DEMAND (million dollars)

Item	2004	2009	2014
Nanotech Health Care Product Demand	906	6500	27700
Pharmaceuticals	406	3000	16600
Diagnostics	465	1100	2200
Medical Product and Devices	35	2400	8900

(*29*)

Nanomedicine taxonomies from 2003 and 2005 give an idea as to what is covered by Nano/NBIC medicine nowadays.

Nanomedicine Taxonomy

Biopharmaceutics
- Drug Delivery
  - Drug Encapsulation
  - Functional Drug Carriers
- Drug Discovery

Implantable Materials
- Tissue Repair and Replacement
  - Implant Coatings
  - Tissue Regeneration Scaffolds
- Structural Implant Materials
  - Bone Repair
  - Bioresorbable Materials
  - Smart Materials

Implantable Devices
- Assessment and Treatment Devices
  - Implantable Sensors
  - Implantable Medical Devices
- Sensory Aids
  - Retina Implants
  - Cochlear Implants

Surgical Aids
- Operating Tools
  - Smart Instruments
  - Surgical Robots

Diagnostic Tools
- Genetic Testing
  - Ultra-sensitive Labeling and Detection Technologies
  - High Throughput Arrays and Multiple Analyses
- Imaging
  - Nanoparticle Labels
  - Imaging Devices

Understanding Basic Life Processes

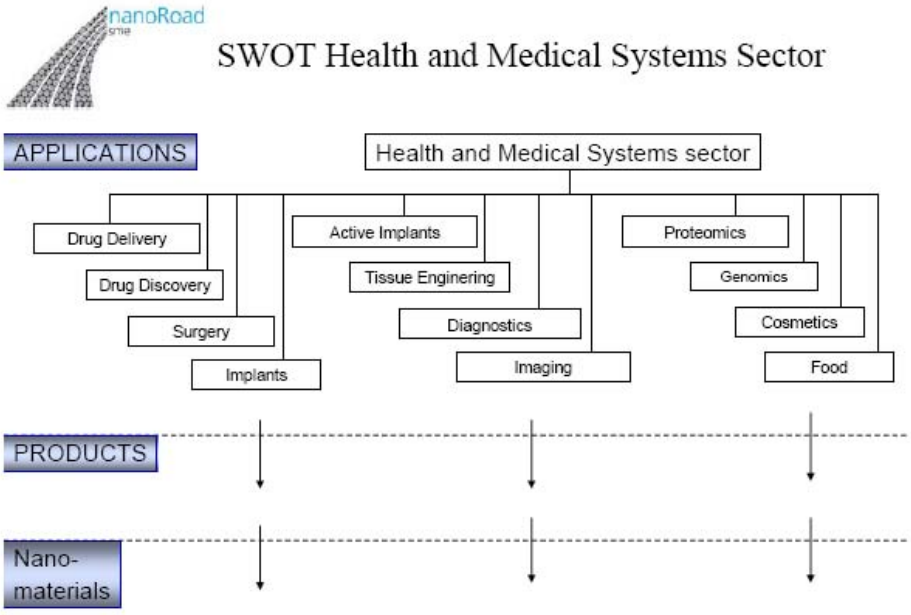
(*30*)

Table 1
A partial nanomedicine technologies taxonomy

Raw nanomaterials	**Cell simulations and cell diagnostics**	**Biological research**
Nanoparticle coatings	Cell chips	Nanobiology
Nanocrystalline materials	Cell simulators	Nanoscience in life sciences
Nanostructured materials	**DNA manipulation, sequencing, diagnostics**	**Drug delivery**
Cyclic peptides	Genetic testing	Drug discovery
Dendrimers	DNA microarrays	Biopharmaceutics
Detoxification agents	Ultrafast DNA sequencing	Drug delivery
Fullerenes	DNA manipulation and control	Drug encapsulation
Functional drug carriers		Smart drugs
MRI scanning (nanoparticles)	**Tools and diagnostics**	
Nanobarcodes	Bacterial detection systems	**Molecular medicine**
Nanoemulsions	Biochips	Genetic therapy
Nanofibers	Biomolecular imaging	Pharmacogenomics
Nanoparticles	Biosensors and biodetection	
Nanoshells	Diagnostic and defense applications	**Artificial enzymes and enzyme control**
Carbon nanotubes	Endoscopic robots and microscopes	Enzyme manipulation and control
Noncarbon nanotubes	Fullerene-based sensors	
Quantum dots	Imaging (cellular, etc.)	**Nanotherapeutics**
	Lab on a chip	Antibacterial and antiviral nanoparticles
Artificial binding sites	Monitoring	Fullerene-based pharmaceuticals
Artificial antibodies	Nanosensors	Photodynamic therapy
Artificial ezymes	Point of care diagnostics	Radiopharmaceuticals
Artificial receptors	Protein microarrays	
Molecularly imprinted polymers	Scanning probe microscopy	**Synthetic biology and early nanodevices**
		Dynamic nanoplatform "nanosome"
Control of surfaces	**Intracellular devices**	Tecto-dendrimers
Artificial surfaces—adhesive	Intracellular assay	Artificial cells and liposomes
Artificial surfaces—nonadhesive	Intracellular biocomputers	Polymeric micelles and polymersomes
Artificial surfaces—regulated	Intracellular sensors/reporters	
Biocompatible surfaces	Implants inside cells	**Biotechnology and biorobotics**
Biofilm suppression		Biologic viral therapy
Engineered surfaces	**BioMEMS**	Virus-based hybrids
Pattern surfaces (contact guidance)	Implantable materials and devices	Stem cells and cloning
Thin-film coatings	Implanted bioMEMS, chips, and electrodes	Tissue engineering
	MEMS/Nanomaterials-based prosthetics	Artificial organs
	Sensory aids (artificial retina, etc.)	Nanobiotechnology
Nanopores	Microarrays	Biorobotics and biobots
Immunoisolation	Microcantilever-based sensors	
Molecular sieves and channels	Microfluidics	**Nanorobotics**
Nanofiltration membranes	Microneedles	DNA-based devices and nanorobots
Nanopores	Medical MEMS	Diamond-based nanorobots
Separations	MEMS surgical devices	Cell repair devices

(*31*)

A nanoroadmap for Nanomedicine in Europe (*28*) has the following taxonomy:



Many Nanomedicine products envisioned or anticipated can be found in a recent report by Wolbring (*32*) and in works noted here and above (*5;27;33-35*).

NANOTECHNOLOGY-NBICS AND DISABLED PEOPLE

Disabled people are often highlighted as the beneficiaries of NBIC-medicine products. NBIC applications and the selling of NBIC health products focuses mostly on offering disabled people medical solutions (prevention or cure/normative adaptation) and might move towards transhumanist solutions (augmentation, enhancement of the human body) but rarely offers social solutions (adaptation of the environment, acceptance, societal cures of equal rights and respect).

Nanotechnology/NBICS applications/products envisioned for disabled people

Many NBICS applications/products are envisioned for disabled people and are under development. The following extended quotation is an excerpt from Wolbring (*32*), a paper that highlights some ideas and products under development.

> For the deaf, we will have systems that provide subtitles around the world. We're getting close to the point where speaker-independent speech recognition will become common. Machines will create subtitles automatically and on the fly, and these subtitles will be a pretty accurate representation of what people are saying. We will have listening systems that allow deaf persons to understand what people are saying. For blind people, we actually will have reading machines within a few years that are not just sitting on a desk, but are tiny devices you put in your pocket. You'll take pictures of signs on the wall, handouts at meetings, and so on. You will be able to wear one

on your lapel and scan in all directions. These devices probably will be used by the sighted as well, because they will allow us to get visual information from all around us. Such devices also will translate the information from one language to another for everyone. We've put together demonstration technology to show just how the information will be transferred back and forth from English to German, from German to French, from French to English, and so on. Exoskeletal aid for physical impairments. Reconnecting broken nerve pathways. Kurzweil explains, "There have been interesting experiments in scanning brain patterns 15 or 20 years after the injury in spinal cord patients. They are asked to perform certain functions—lift your leg, walk across the room. The brain-pattern activity was the same as in a non-disabled person, but obviously it was not communicating, because the pathways were broken. Still, it will be quite feasible to pick up the patterns in the brain and wirelessly communicate them to the muscles, completely bypassing the nervous system that's no longer functioning." Ultimately, we will be able to create the muscles as well. We are creating muscle analogs for robots, but those could be used for disabled persons as well. There are other challenges—creating a skeletal system to replace one that may not be up to the task, dealing with the cardiovascular implications. These are complex projects, but I believe we will see profound steps forward by 2010. By 2020, I think we will have largely overcome the handicaps of spinal cord injuries. Enhancing our own intelligence: there are many people walking around now who are essentially cyborgs and have computers in their brains interfacing with their biological neurons. According to Kurzweil, the Food and Drug Administration just approved a neural implant for Parkinson's disease that replaces the portion of the brain destroyed by that disease" (*36*).

In the 2001 report on NBIC (*37*), one reads the following about the future capabilities of nanotechnology, in particular, the use of nano implant devices to self-monitor physiological well-being and dysfunction:

"As the scales of nanofabrication and nanotransducers approach those of the critical biomolecular feature sizes, they give the technologist the toolset to probe and control biological functions at the most fundamental 'life machinery' level. By the same token, this technology could profoundly affect the ways we manage our health. One outcome of combining nanotechnology with biotechnology will be molecular prosthetics — nano components that can repair or replace defective cellular components such as ion channels or protein signaling receptors. Another result will be intracellular imaging, perhaps enabled by synthetic nano-materials that can act as contrast agents to highlight early disease markers in routine screening. Through self-delivered nano-medical intervention, patients in the future will be able in the comfort of their homes to perform noninvasive treatments autonomously or under remote supervision by physicians. Metabolic and anatomical monitoring will be able to give humans the capability to track the energy balance of intake and consumption. Monitoring high-risk factors will be able to facilitate early diagnosis, when medical treatments can be most effective. Information systems designed to present medical data in ways that are intelligible to laypersons will allow anyone to monitor his or her health. As a result of NBIC-enabled 'wonder medicines,' there will be a need to develop technology and training modalities to make the patient an essential partner in the process of health monitoring and intervention. As the population ages, more and more age-related diseases and deteriorating functions (e.g.,

hearing, memory, muscle strength, and sight) will be prevalent; an obvious example is Alzheimer's disease. Some of these dysfunctions are due to molecular changes over time, and some are due to the natural decay of bodily functions. NBIC will provide ways to slow down the aging process or even reverse it" (*37*).

Other visions in the same paper relate to nano-medical research and intervention monitoring and robotics. The convergence of nano-bio-info-cogno technologies will enhance the toolset for medical research and allow medical intervention and monitoring through multifunctional nanorobots (e.g., a nano brain surveillance camera). A range of nano-enabled unobtrusive tools will facilitate research on cognitive activities of the brain.

In the article, "Quality of Life of Disabled People Using Converging Technologies," in the same book:

"'It is understood that NBIC should be used in a way that diminishes the discrimination against disabled people, advances their acceptance and integration into society, and increases their quality of life. NBIC has the potential to give disabled people, and this includes many elderly, the ability to choose between different modes of information output, whether visual, audio, print, or others, as all these modes can be offered routinely at the same time. It has the potential to change computer interface architecture so that disabled people, including those who are blind, sight impaired, dyslexic, arthritic, immobile, and deaf, can access the Internet and its web pages as transparently and quickly as able-bodied people by means of, for example, holographic outputs; force-feedback, vibrotactile, vastly improved natural speech interfaces; and real-time close captioning. Multimodal access to data and representations will provide a cognitively and perceptually richer form of interaction for all persons, regardless of impairment, handicap, or disability. It will allow for more flexibility in the mode of working (from home or a company building or elsewhere) and representation (in person or virtual). …NBIC will allow for improving assistive devices for disabled people. …NBIC will greatly improve the functionality and design of houses, allowing voice command, intelligent applications, etc., that enable disabled (and elderly) people to be more independent. …NBIC has the potential to change the public space to make it much more user friendly and inclusive. Means will include IT advances to enable wearable computers for use in everyday living (e.g., finding when the next bus is due or where it is now); creation of smart environments (e.g., Remote Auditory Signage Systems [RASS] like talking signs, talking buses, etc., to facilitate way finding, business/object location identification, recognition of mass transit services, and intermodal transfer); use of IT and cognitive technology to develop voice-activated personal guidance systems using GPS and GIS; and multimodal interfaces to assist travel and environmental learning. …NBIC has the potential to improve communication on a global scale (e.g., universal translation devices), which would allow for a greater exchange of knowledge among people and a faster dissemination of advances in NBIC' (*38*).

Brain–machine interfaces. Scientists have demonstrated in 2002 that human thoughts can be converted into radio waves and used by paralyzed people to create movement (*39*). "Unable to move, Matthew Nagle can play Tetris, draw and turn on the TV using the chip in his brain" (*40*). One team

implanted miniature transmitters into the brains of terminally ill people suffering from degenerative conditions that rendered them unable to communicate. Their thoughts alone enabled them to create movement. It was said: "'Ultimately the technology will be used for people whose spinal cords are destroyed in accidents or those handicapped by strokes" (*39*). "'Scientists in Australia have developed a 'mind switch' (*41*) that enables people to activate electrical devices (e.g. turn on a radio or open doors) by thinking" (*42*).

Following is the work of the IDIAP Research Institute, originally referred to as "Institute Dalle Molle d'Intelligence Artificielle Perceptive" (Dalle Molle Institute for Perceptual Artificial Intelligence). As they state in a recent publication:

"Brain activity recorded non-invasively is sufficient to control a mobile robot if advanced robotics is used in combination with asynchronous EEG analysis and machine learning techniques. Until now brain-actuated control has mainly relied on implanted electrodes, since EEG-based systems have been considered too slow for controlling rapid and complex sequences of movements. We show that two human subjects successfully moved a robot between several rooms by mental control only, using an EEG-based brain-machine interface that recognized three mental states. Mental control was comparable to manual control on the same task with a performance ratio of 0.74" (*32;43*).

The report goes on, "The Dalle Molle Institute for Perceptual Artificial Intelligence is not the only one working on brain machine interfaces. There are others, such as the company Cyberkinetics, which received FDA approval to test their product 'Brain Gate' (*44*). Researchers at Duke University Medical Center in Durham, North Carolina, are currently developing a wireless neuroprosthetic that could potentially control robotic limbs for quadriplegics (*45-49*). They are also planning a brain-controlled electric wheelchair and a brain-operated keyboard (*50*). Recently a whole issue of the journal of the Banff Centre of the Arts was dedicated to nanotechnology and the dream home" (*51;52*).

The preceding discussion on brain–machine interfaces relates to disabled people; however, it is logical to expect that these devices will also be used by non-disabled people as a means to control their environment, especially if the brain–machine interface is non-invasive and no implants are needed as in the working model of the Dalle Molle Institute for Perceptual Artificial Intelligence.

MIT Group Develops Mind-Reading Device.
Three researchers at the MIT Media Lab have developed a device that "reads minds" and alerts wearers to the emotional state of the person with whom they are conversing. The device is called the Emotional Social Intelligence Prosthetic. The research team hopes it will help people with autism learn to better read the social cues of others (*53*).

Brain Cells Fused with Computer.
The line between living organisms and machines has just become a whole lot blurrier. European researchers have developed "neuro-chips" in which living brain cells and silicon circuits are coupled together. The achievement could

one day enable the creation of sophisticated neural prostheses to treat neurological disorders or the development of organic computers that crunch numbers using living neurons(*54*).

Bionic implants. "When Kevin Warwick lifted his finger, his wife Irena felt as if a bolt of lightning ran down her palm and into her own finger. In what they billed as the first direct link between nervous systems, the couple had electrodes surgically implanted in their arms and linked by radio signals to a computer. Blindfolded for the experiment, they could feel when their spouse's finger moved" (*55-57*). Other examples of bionic implants are described by Thomas (*58*).

Bionic ear (*59;60*). Advanced Bionics introduced the HiRes 90K implant over a year ago and since then more than 2600 implants have been manufactured. The HiRes 90K implant has had an explant rate of 1.1% at 12 months. As of 2000, more than 20,000 people worldwide have bionic ears (*61*).

"The market for cochlear implants is already well established; however, some problems with the technology remain such as interference with strong magnetic fields and the risk of infection, eczema, or dizziness. Nano-technology can be applied to antimicrobial coatings on hearing aids including cochlear implants. Nanostructured coatings, including diffusable silver ions that are released slowly from the coating to prevent infections in the ear, have been developed" (Morrison, 2003).

There are two methods of administering antimicrobial remedies to the inner ear following cochlear implant operations: coatings or fluid-based drug delivery systems (*62*).

The Bionic Ear Institute in Australia is building an implant for the inner ear that will shock damaged nerves back to health. A small pump showers the nerves with stimulating chemicals while electrodes excite the cells to keep them alive (*63*).

Bionic eyes (*64*). Retinal implants are being developed to partially restore sight for blind patients who have diseases that destroy the photoreceptor cells of the retina at the back of the eye but leave the visual nerve and visual cortex intact. These diseases include retinitis pigmentosa, Usher syndrome, and macular degeneration. In the EU, there are 70,000 to 100,000 patients with retinitis pigmentosa and 2.1 to 2.2 million patients with macular degeneration (*65;66*).

Retinal implant research projects. Since the late 1990s, there have been at least two fundamental retinal implant research projects in the USA and a further two in Germany, funded by the Federal Ministry for Education and Research. The German projects are the Epiret project, which aims to develop a retinal implant located at the back of the ganglion cells that connects directly to the optic nerve, and the Subret project, which aims to develop a retinal implant located in place of the lost photoreceptor cells. The projects have been running in two phases between 1995 and 2003 (*67*).

Nanotechnology retinal implants. Dr Martin Stelzle, head of Physical Chemistry and Sensors Group, NMI Naturwissenschaftliches und Medizinisches

Institut in Reutlingen, Germany, is developing new retinal implants using nanotechnology (*68*).

Next generation autonomous wheelchair control. Research is under way to add new capabilities to a wheelchair such that the wheelchair knows its environment, senses where it is and where it must go, and avoids any obstacles. This design challenge is broken into four major steps: wheelchair control, environment recognition, route planning, and obstacle avoidance (*69*).

Bionic legs and arms. Many companies work on the development of bionic legs and arms (*70-73*). The potential market is huge: roughly 260,000 people undergo lower limb amputations in the United States each year. And that's less than half the G8 market (*74*). Victhom's focus is on active amputees from 25 to 55; by the company's calculation, 300,000 above-the-knee amputees in the G8 fit the bill, with up to 40,000 new cases each year (*73*). About 8% of the estimated 387,500 amputees in the United States are those that have lost their arms (*75*). The Defense Sciences Office (DSO) of the Defense Advanced Research Projects Agency (DARPA) just asked for proposals for upper-extremity prosthesis (*76*). The number of implants in use in the USA indicates their importance to health care and the economic impact of the biomaterials industry. For example, it was estimated in 1988 that 674,000 adults in the US were using 811,000 artificial hips. It was also estimated that 170,000 people worldwide received artificial heart valves in 1994 (*77*).

Bionic knee. There is a growing need for bionic knees in part because of skyrocketing diabetes rates and because of advances in medicine which have led to more people surviving car accidents and motorcycle accidents (*78*). Rheo-Knee, which costs $30,000, uses artificial intelligence—tiny sensors that analyze the knee 1000 times per second, allowing it to adjust to any step or misstep (*79*). The 3DKnee is another knee implant from which to choose (*80*).

Neural prostheses. Neural prostheses are technical systems that partially substitute neural body functions after traumatic lesions or neurological disorders (*81*).

Spinal cord prostheses. More than 200,000 people in the USA alone live with Spinal Cord Injury (*82;83*). Repairing spinal cords means finding a way to get nerve cells to grow back across the gap in a spinal cord that has been severed. Nanotechnology is employed to achieve this goal (*84*).

Speech. On the betterhuman.com webpage one reads: “A system that converts nerve signals in the throat into computerized speech could soon allow people to speak without saying a word.” “The system that the researchers developed is a **neural interface**—a type of data link between the human **nervous system** and an external device, such as a computer or a remote-controlled machine. It uses sensors placed under the chin and on either side of the “Adam's apple”—the laryngeal prominence—to gather subvocal nerve signals and transfer them to a **processor**, then to a computer program that translates the signals into words. Subvocal speech is characterized by movement of the lips or other speech organs without

accompanying audible sounds. "A person using the subvocal system thinks of phrases and talks to himself so quietly, it cannot be heard, but the tongue and vocal chords do receive speech signals from the brain," says Jorgensen.(*85;86*).

Cranial, neural, and other implants. Repairing severe human skull injuries requires customized cranial implants designed to improve the condition of patients suffering from brain-related diseases, mainly by supplying biochemicals to the brain and monitoring the effects, for example, in the alleviation of the effects of Parkinson's disease. Other neural implants are pacemakers, bladder stimulators, drug dosage systems (Medtronic's). In regards to Parkinson's, one reads on Medtronic's webpage, "What is Active® Parkinson's Control Therapy? Active Parkinson's Control Therapy from Medtronic is one of the most significant advances in the treatment of Parkinson's disease in more than 30 years offering an innovative treatment approach. The treatment uses two surgically implanted medical devices, similar to cardiac pacemakers, to deliver electrical stimulation to precisely targeted areas on each side of the brain. Continuous stimulation of these areas blocks the signals that cause the disabling motor symptoms of the disease. As a result, many patients achieve greater control over their body movements. Since 1997, more than 14,000 people worldwide have benefited from Active Therapy for Essential Tremor and Parkinson's disease. The total cost of Active Therapy varies significantly but often ranges on average from $25,000 to $30,000 per side for the device and the associated physician and hospital fees. Under the new policy, patients will still pay deductibles, coinsurance and co-payments, but Medicare will provide coverage for this therapy" (*87*).

"Finally, for the implant procedure ratio for deep brain stimulator therapy, which is used to control tremors related to Parkinson's disease, there are 21 procedures/million in Belgium, 13/million in Australia, 9/million in the US, and 5/million in Canada" (*88*). Nanotechnology is also involved in bionic implants such as artificial joints (*89*), artificial muscles (*90*), artificial noses and tongues, nose on a chip (*91;92*), bioartificial kidney, artificial liver (*93;94*), artificial lungs (*95*), artificial discs (*96*), and so on (*97*).

And there is more

ETC recently published a report on Nanomedicine with many more examples(*98*).

Furthermore, there are NBIC processes and products which will impact on disabled people due their stigmatizing capacity such as NBIC-enabled genetic and non-genetic prebirth, pre-implantation and after-birth diagnostics and artificial wombs (if they are ever functional).

DISABLED PEOPLE, NBICS AND DEVELOPMENT

More than 80% of disabled people live in developing countries, 40% of them between the ages of 10-24 (*99*). Disabled people have limited access to education (as low as 3%), employment and basic health care (as low as 2%), and experience profound economic and social exclusion. Most disabled people live in poverty, prevented from fully participating in their families and communities and from benefiting from their socio-economic rights (*100*). Eliminating world poverty and meeting the Millennium Development Goals (MDG) is unlikely to be achieved unless the rights and needs of disabled people are taken into account (*101*).

A list of top ten nanotechnologies for development (*102*) and a list of top ten biotechnologies for improving health in developing countries were recently published (*103*).

The question, however, arises whether the nano- and bio-technologies in these lists are designed, implemented, governed and developed in such a way that they are taking into account the specific needs and realities of disabled people and whether they meet the development needs of disabled people.

Nanowater

Water treatment ranks third in the "Top Ten Nanotechnologies" uses for development list. (*102*) Nanotechnology can be involved with water in numerous ways, including desalination, detoxification, sanitation, decreased use of water, hydrogen usage, and hydro-generated power, to name a few(*104*).

Nanotechnology should be able to help the more than 1 billion people in the world who lack access to clean water, and the 2.6 billion who lack access to sanitation (*105*). Halving the number of people without access to water and sanitation is on the list of MDGs (*105*). However, if it is to help, social determinants have to be taken into account to ensure distribution and affordability of the technology. Just by itself nanotechnology will do nothing to lead to accessible clean water and sanitation(*105*).

Furthermore, how does this nanotechnology for water play itself out for disabled people? The question has to be answered with a "Not well." Disabled people – from both the North and the South – have rarely been involved in the discourse around clean water and sanitation. Initiators and organizers of stakeholder meetings rarely think of disabled people as stakeholders. It is rare that disabled people are identified as a group affected by the particular issues related to water. The 2003 (*106*) and the 2006 (*107*) reports on water written by the World Water Assessment Programme were able to ignore disabled people and their needs in regards to water and sanitation in both reports despite being informed numerous time after the first report that disabled people are missing. Clean water and sanitation is inadequate if delivery does not take into account the different modes of functioning of disabled people. Disabled people have clear ideas about what they need, but their expertise is ignored in the discourse.(*105;108*)

It is insufficient just to highlight techno-solutions such as nanotechnology for clean water. A technology is only as good as society allows it to be and as good as the input that is considered in defining the problem. As it stands, the nanowater discourse will do little for the development of disabled people and, as nano and NBICS are governed the same, the same can be concluded for most of the NBICS products existing and appearing and for the nano and bio lists mentioned above.

Furthermore if the nanowater discourse in general is any indication social determinants to implement nano-water technologies are not taken into account and without them nano-water technology will fail.

Conceptual and practical issues raised by nanotechnology

However, aside from the non-involvement of disabled people in many areas of NBICS, there are other issues, some clearer than others.

Impacts of Nanotechnology and NBICS in general

Human Security: NBICS and its governance impacts on human security which entails Economic Security; Food Security; Health Security; Environmental Security, Personal Security, Community Security; Political Security; Freedom from Fear; and Freedom from Want. "Human security is concerned with safeguarding and expanding people's vital freedoms. It requires both shielding people from acute threats and empowering people to take charge of their own lives. Needed are integrated policies that focus on people's survival, livelihood and dignity, during downturns as well as in prosperity"(*109*).

"The Commission for human security recommends that the tasks of advancing human security on all fronts start by addressing some of the basics such as

- • Protecting people in violent conflict.
- • Protecting people from the proliferation of arms.
- • Supporting the human security of people on the move.
- • Establishing human security transition funds for post-conflict situations.
- • Encouraging fair trade and markets to benefit the extreme poor.
- • Providing minimum living standards everywhere.
- • According high priority to universal access to basic health care.
- • Developing an efficient and equitable global system for patent rights.
- • Empowering all people with universal basic education, through much stronger global and national efforts.
- • Clarifying the need for a global human identity while respecting the freedom of individuals to have diverse identities and affiliations" (*109*).

NBICS and how it is governed impacts on the ability to address these basics. Furthermore, NBICS is increasingly leading to products which pose new and unique challenges to human security and that will go beyond the traditional threats and hopes for human security. Consider, for example, the need to address ability security (the security that ones has a livelihood independent of once ability and whether one enhanced ones body with the latest product) and self-identity security (that one can chose for oneself whether one sees ones body as deficient or not and is not forced to accept negative perception others have of oneself).

Personal Safety: Every product and process enabled by the different areas of nanotechnology and the converging of nano with other technologies will affect everyone if the products are unsafe. On the one hand, it might affect more the poor and the disabled, especially the non-competent ones, if they are preferably used as research subjects and if the products are tried out on them first. On the other hand, it might impact the well off first, in certain settings, because they can buy certain products that the poor (disabled or not) cannot afford. In addition, it might impact the non-disabled more if the production process is unsafe as there are many more non-disabled than disabled workers

Environmental Safety: Every product and process enabled by the different areas of nanotechnology and the converging of nano with other technologies will impact on everyone if the products are environmentally unsafe.

Military, surveillance, security, increase in individuals' destruction potential: Every product and process enabled by the different areas of nanotechnology and the converging of nano with other technologies that might be used by the military and applied for surveillance, for security, or to increase the destruction potential of individuals will impact everyone.

Nanoformulated and atomic commodities: Moving from nature-based commodities (i.e., copper, rubber) towards nano-formulated commodities towards atomic commodities (molecular manufacturing) will impact first low-wage workers and then other workers as it will change the commodity market and, in the end, the nature of trade. It will also impact disabled people, but as most of them are unemployed or are not employed within commodity work, they might feel the effect later than other groups or not at all.

Availability: Most of the products will very likely lead to a distribution inequality based on available disposable income. In general, this is more an income divide than an impact specifically related to disabled people. However, more than 80% of disabled people live in low-income countries (*99*); disabled people have limited access to education (as low as 3%), to employment and to basic health care (as low as 2%); they experience profound economic and social exclusion. In addition, most disabled people live in poverty and are thereby prevented from fully participating in their families and communities and from benefiting from their socio-economic rights. For these reason, the income divide might affect disabled people more simply because they are over represented among the poor.

Impacting disabled people

Nanotechnology and NBICS have an impact on disabled people in at least four main ways.

Impact of NBICS on disabled people
NBICS may develop tools to <u>adapt</u> the environment in which disabled people live and to give disabled people tools that would allow them to deal with environmental challenges. This side of S&T would make the life of disabled people more liveable without changing the identity and biological reality of the disabled person
NBICS may develop tools that would <u>diagnose</u> the part of disabled people's biological reality seen by others as deficient, defect, impaired and 'disabled' thus allowing for preventative measures
NBICS may develop tools that would <u>eliminate</u> that portion of disabled people's biological reality seen by others as deficient, defect, impaired and 'disabled'.
NBICS may be a target for - and an influence upon - the discourses, concepts, trends and areas of action that impact disabled persons (*110*). **Discourses:** • The discourse around the term human security • The religious discourse (*111*)forthcoming) • The politics of Biodiversity • The politics of inequity (2006a) • The politics of the ethics discourse.(*112;113*) • The politics of law:(*114;115*) • The Politics of raising the acceptance level for a given technology • The Politics of setting goals and priorities • The Politics of language(*32*) • The Politics of self perception and identity (Body politics)(*10;32;116*) • The politics of red herrings • The politics of interpreting International treaties(*32*) • The politics of governance • The Politics of evaluation, measuring, analysis, and outcome tools(*32*) **Concepts:** • Self Identity Security(*117*)

- Ability Security forthcoming
- Cultural Identity/Diversity (*118*)
- Morphological Freedom and morphological judgement (Sandberg, 2001; Wolbring, forthcoming)
- Freedom of Choice and tyranny of choice (forthcoming)
- Duty to fix oneself (*119*)
- Duty to Know (*119*)
- Parental Responsibility (*120*)
- Societal Responsibility

Trends:

- Change in the concepts of health, disease and 'disability'/'impairment' (*32*)
- The appearance of enhancement medicine and the acceptance of beyond species-typical functioning(*32*)
- Moving from curative to enhancement medicine; decrease in curative medicine and the appearance of the transhumanist/enhancement burden of disease (*32*)
- Moving from human rights to sentient rights (forthcoming)
- Moving from androcentrism, abilitynormocentrism and anthropocentrism to intellicentrism, cognocentrism, transabilitycentrism will be enhancements to the endpoint of transhumanism (forthcoming)
- Moving from morphological freedom to morphological judgement (forthcoming)
- The appearance of the techno poor disabled(*121*)
- Moving from Freedom of Choice to tyranny of choice judgement (forthcoming a)

Areas of Action:

- Nanotechnology/NBIC for Development
- Nanotechnology/NBIC and the UN Millennium Development Goals
- Nanotechnology/NBIC and Global medical and social health
- Nanotechnology/NBIC and Accessibility
- Nanotechnology/NBIC and Law
- Nanotechnology/NBIC and Water and Sanitation
- Nanotechnology/NBIC and Disaster Management
- Nanotechnology/NBIC and Weapons/War
- Nanotechnology/NBIC and Ethics/philosophy
- Nanotechnology/NBIC and Social science/anthropology
- Nanotechnology/NBIC and Community
- Nanotechnology/NBIC and Networking

All of the above discourses, concepts, trends and areas of actions impact on disabled people and others.

NANO/NBICS GOVERNANCE AND DISABLED PEOPLE

Key issues need to be addressed in order to unlock the potential of nanotechnology and converging technologies for the world's majority. A variety of documents are available which examine what good nano/NBICS governance might entail(*122-126*) (*127;128*). However, it is striking that disabled people are, for the most part, not mentioned.

The missing disabled people

In recent searches of Google, Google Scholar and a variety of academic database clusters (Academic Search Premier, Ovid Cluster of Databases, Cambridge Scientific Cluster of Databases), the search term "nanotechnology and disabled people" had 5% or fewer the number of hits for "nanotechnology and women," the social group with the highest number of hits. It is interesting that "nanotechnology and patients" ranks second. The same pattern was true for the term "science and technology studies and disabled people," which had 5% or fewer hits than "science and technology studies and women," again the social group with the highest number of hits. It is interesting, again, that "science and technology studies and patients" ranks second. The data are available in detail in a book chapter on nanoengagement recently submitted (Wolbring, n.d.).

Even the concept of "upstream engagement" - a concept which is supposed to be about the involvement of members of society and is supposed to "embed social values in the design stages of innovation" (Demos, See through Science) - does not think about disabled people. Indeed, in relation to disabled people, one has to ask the questions "With whom, for whom and by whom?"; "Whose social values?"; "Upstream of what?"; and "Upstream engagement when?"

With a Google keyword search recently, "upstream engagement" alone had 534 hits and in combination with "women" had 116 hits; "the south" had 56 hits; "the poor" had 81 hits, but "disabled people" had only 20 hits and "people with disabilities" had 8 hits.

The same general proportions were found under Google Scholar. The keywords "upstream engagement" alone had 27 hits and in combination with "women" had 8 hits; "the south" had 5 hits; "the poor" had 6 hits but "disabled people" had only 1 hit as did "people with disabilities."

Within MSN search keyword combination, "upstream engagement" alone had 832 hits and in combination with "women" had 170 hits; "the south" had 93 hits; "he poor"' had 211 hits but "disabled people" had only eight hits and "people with disabilities" had four hits.

The same pattern holds true for the academic database clusters (Academic Search Premier, Ovid Cluster of Databases, and Cambridge Scientific Cluster of Databases).

These results indicate that disabled people are invisible in the NBICS discourse on many levels.

The inclusion of disabled people – where the term is used to identify more than disabled patients - in the governance of science and technology in general and nano and NBIC in particular is essential for "disabled" and "non-disabled people." The goal of involving disabled people fits well with the language from six major health promotion conferences. Note, for example, the recent statement by the Global Forum for Health Research at the conclusion of Forum 8 Mexico City, 1in November 2004 (*129*), the UN Convention on the rights of disabled people (text just agreed upon) (*130*), many other positive national legal

advances (*131*) and the suggestions about disabled people in other international documents, such as the final documents of the UNESCO World Conference on Science.

Declaration on Science:

25. ....there are barriers which have precluded the full participation of other groups, of both sexes, including disabled people, indigenous peoples and ethnic minorities, hereafter referred to as “disadvantaged groups”...

34. Science education, in the broad sense, without discrimination and encompassing all levels and modalities is a fundamental prerequisite for democracy and for ensuring sustainable development. In recent years, worldwide measures have been undertaken to promote basic education for all. Special attention is still required for marginalized groups. It is more than ever necessary to develop and expand science literacy in all cultures and sectors of society as well as reasoning ability and skills and an appreciation of ethical values, so as to improve public participation in decision-making related to the application of new knowledge.

42. Equality in access to science is not only a social and ethical requirement for human development, but also a necessity for realizing the full potential of scientific communities worldwide and for orienting scientific progress towards meeting the needs of humankind. The difficulties encountered by women, constituting over half of the population in the world, in entering, pursuing and advancing in a career in the sciences and in participating in decision-making in science and technology should be addressed urgently. There is an equally urgent need to address the difficulties faced by disadvantaged groups which preclude their full and effective participation (*132*).

Science Agenda-Framework for Action (*133*):

17. Scientists, research institutions and learned scientific societies and other relevant non-governmental organizations should commit themselves to increased international collaboration including exchange of knowledge and expertise. Initiatives to facilitate access to scientific information sources by scientists and institutions in the developing countries should be especially encouraged and supported. Initiatives to fully incorporate women scientists and other disadvantaged groups from the South and North into scientific networks should be implemented. In this context, efforts should be made to ensure that results of publicly funded research will be made accessible.

59. Governments should promote the further development or setting up of national statistical services capable of providing sound data, disaggregated by gender and disadvantaged groups, on science education and R&D activities that are necessary for effective S&T policy-making. Developing countries should be assisted in this respect by the international community, using the technical expertise of UNESCO and other international organizations.

79. The full participation of disadvantaged groups in all aspects of research activities, including the development of policy, also needs to be ensured.

81. Governments and educational institutions should identify and eliminate, from the early learning stages on educational practices that have a discriminatory effect, so as to increase the successful participation in science of individuals from all sectors of society, including disadvantaged groups.

91. Special efforts also need to be made to ensure the full participation of disadvantaged groups in science and technology, such efforts to include:

- removing barriers in the education system;
- removing barriers in the research system;
- raising awareness of the contribution of these groups to science and technology in order to
    - overcome existing stereotypes;
    - undertaking research, supported by the collection of data, documenting constraints
    - monitoring , implementation and documenting best practices;
    - ensuring representation in policy-making bodies and forums.

Practical issues in engaging the disability community

Involving disabled people is not a simple task. A variety of practical issues have to be resolved if a meaningful continuous engagement of disabled people in NBIC and nano is to become a reality.

1. The lack of general education and, in particular, lack of knowledge of the issues around nanotechnology and NBIC
2. The absolute underrepresentation of disabled people within academia, government policy branches, international and intergovernmental agencies, non disabled people NGO's and most places where the discourse around Nano and NBIC takes place
3. The fact that most disabled people are overwhelmed by the daily struggle for survival - fighting for food, against poverty, for access to water and sanitation, for access to education and healthcare and for being seen as a member of society and the community - makes the issues around nanotechnology and NBIC seem to be of low priority
4. The lack of support for disabled people from the human rights and other movements and the existence of a human rights hierarchy
5. That disabled people are, for the most part, seen through the lens of a medical model
6. That many disabled people distrust academics – whether non-disabled and disabled
7. That often academic disabled people avoid disabled people and their situation
8. Silo thinking of groups and issues
9. A hierarchy exists within the social group of disabled people
10. Due to the low level of education, most disabled people do not have the language skills needed to understand documents and other media, such as webpages, not in their mother tongue
11. Physical access issues exist for a variety of disabled people, such as the inaccesibility of 98% of webpages for blind people, the lack of interpreters in most verbal communications, lack of closed captioning in most video clips and the inaccessibility of buildings in which relevant meetings take place
12. Diversity and range of self understanding and self identity of disabled people from "I am defective" to "I am a variation"
13. The bias of language
14. The clash of social values

Some initial suggestions as what has to change

To ensure the involvement of "traditional" disabled people and the '"techno poor"disabled, one would need a radical departure from behaviour patterns towards disabled people as evident today in society at large, human rights groups, policy makers, individuals, industry, politicians, academics, especially ethicists, and marginalized groups.

To stop the inequalities that come with body enhancement technologies, transhumanist philosophies and the NBIC discourse as it is today, one has to question able-ism, the network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and, therefore, essential and fully human. In this framework, disability/impairment is seen as a diminished state of being human (*4*).

A useful tool to tackle the bias of language in the existing discourse might be the BIAS FREE framework. BIAS FREE is an acronym for Building an Integrative Analytical System For Recognizing and Eliminating InEquities (*134*), a tool which was designed to provide a unified approach to detecting biases that derive from any and all social hierarchies. (Cf. the following tables.)

TABLE Ia
Maintaining an Existing Hierarchy, THE BIAS FREE FRAMEWORK

Type of Bias	Diagnostic Questions	Solutions	Research Component	Types of Hierarchy
H—Maintaining an Existing Hierarchy **Is dominance of one group over the other in any way justified or unproblematic?**	**H1 Denying hierarchy: Is the existence of a hierarchy denied in spite of widespread evidence to the contrary?** **H2 Maintaining hierarchy: Are practices or views that are based on a hierarchy presented as normal or maintained?** **H3 Dominant perspective: Is the perspective or standpoint of the dominant group adopted?** **H4 Normalization: Are norms derived from the dominant group and then applied to the nondominant group without questioning their relevance?** **H5 Pathologization: Is the non-dominant group defined as deficient when it differs from the norms derived from the dominantgroup?** **H6 Objectification: Is stripping people of their intrinsic dignity and personhood presented as normal or unproblematic?** **.H7 Victim blaming: Are victims of personal or societal/systemic violence blamed and held accountable?** **H8 Appropriation: Is ownership claimed by the dominant group for entities that originate(d) in or belong to the nondominant group?**	**Acknowledge the existence of a hierarchy; question and reject its validation** **Question and problematize expressions of hierarchies.** **Respect and accept the perspectives of non-dominant and dominant groups.** **Acknowledge diversity; exclude norms derived from a social hierarchy.** **Challenge the norm and address the reasons given for defining the group as deficient.** **Recognize that every human is a person with intrinsic dignity and human rights that are inviolable and must be protected.** **Do not blame victims; identify individual, societal and sys-temic violence; and hold accountable those responsible.** **Acknowledge and respect original ownership.**	**Title** **Abstract** **Executive summary Literature review Research proposal/call for proposal** **Research question and design** Research methods **Data analysis and interpretation** **Concepts** **Language** **Policy recommendations**	Gender Disability **Race/Ethnicity** **Class** **Caste** **Age** **Religion** **Sexual orientation** **Geographic location** **Income** **Health status (among others)**

TABLE Ib
Failing to Examine Differences, THE BIAS FREE FRAMEWORK

Type of Bias	Diagnostic Questions	Solutions	Research Component	Types of Hierarchy
F—Failing to Examine Differences Is membership in a non-dominant/ dominant group examined as socially relevant and accommodated?	**F1 Insensitivity to difference:** Has the relevance of membership in dominant/ non-dominant group been ignored?	Always determine the relevancy of dominant/non-dominant group membership; include group membership as an analytical variable throughout the activity so that its relevancy can be assessed.	**Title** **Abstract** **Executive summary** **Literature review** **Research proposal/call for proposal** **Research** question and design Research methods Data analysis and interpretation Concepts Language Policy recommenda-tions	Gender Disability **Race/ Ethnicity** **Class Caste** **Age** **Religion** **Sexual orientation** **Geographic location** **Income** **Health status** **(among others)**
	F2 Decontextualization: Has the different social reality of dominant and non-dominant groups explicitly been considered?	Explicitly examine the context with respect to dominant/non-dominant group membership and identify and analyze differences following from this.		
	F3 Over-generalization or universalization: Is information derived from dominant groups generalized to non-dominant groups without examining if it is applicable to the non-dominant groups?	Acknowledge information about the dominant group, and make efforts to obtain information about the non-dominant group.		
	F4 Assumed homogeneity: Is the dominant or non-dominant group treated as a uniform group?	Acknowledge and take into account differences within dominant and non-dominant groups.		

TABLE Ic
Using Double Standards, THE BIAS FREE FRAMEWORK

Type of Bias	Diagnostic Questions	Solutions	Research Component	Types of Hierarchy
D—Using Double Standards Are nondominant/domina nt groups dealt with differently?	**D1 Overt double standard:** Are nondominant and dominant groups treated unequally?	Provide equal treatment to members of dominant and non-dominant groups to increase equity.	**Title** **Abstract** **Executive summary** **Literature review** **Research proposal/call for proposal** **Research** question and design Research methods Data analysis and interpretation Concepts **Language** **Policy recommenda**- tions	Gender Disability **Race/ Ethnicity** **Class Caste Age** **Religion** **Sexual orientation** **Geographic location** **Income** **Health status (among others)**
	D2 Underrepresentation or exclusion: Are non-dominant groups under-represented or excluded?	Include non-dominant groups to verify their relevancy.		
	D3 Exceptional under-representation or exclusion: In contexts normally associated with non-dominant groups, but pertinent to all groups, is the dominant group underrepresented or excluded?	Appropriately represent and/or include dominante groups in issues of relevance to them that have been stereotyped as being important only (among others) for a non-dominant group.		
	D4 Denying agency: Is there a failure to consider nondominant/dominant groups as both actors and acted upon?	Examine ways in which dominant and non-dominant groups are both acting as well as acted upon.		
	D5 Treating dominant opinions as facts: Are opinions expressed by a dominant group about a nondominant group treated as opinion or fact?	Treat opinions expressed by dominant groups about non-dominant groups as opinions, not fact.		
	D6 Stereotyping: Are stereotypes of non-dominant/ dominant groups treated as essential aspects of group membership?	Treat stereotypes as stereotypes, not as truths, and work towards abolishing them or ensure they are excluded.		
	D7 Exaggerating differences: Are overlapping traits treated as if they were characteristic of only non-dominant / dominant groups?	Document both the differences and the similarities between members of non-dominant and dominant groups.		
	D8 Hidden double standard: Are different criteria used to define comparable facts with the effect of hiding their comparability?	Ask whether there might be a hidden double standard by looking for non-obvious parallels. One way of achieving this is by asking what form the phenomenon identified within one group might take within another group.		

In addition to tackling the bias in languages and social hierarchies evident in the discourse around new and emerging technologies, a new science and technology policy and research agenda is called for to address:

1. The variety of self-understanding of disabled people and the variety of understandings of the term disability
2. The needs of disabled people and other marginalized groups
3. The emergence of the transhumanist/enhancement model of health and disease
4. The increased medicalization/transhumanisation of human beings and their characteristics
5. The negative impact of ableism on disabled people
6. The appearance of the techno poor disabled, where "techno poor disabled" are the people who cannot afford the bodily ability enhancements that are/will be made possible by NBICS and who are, therefore, perceived as disabled in the deficiency meaning
7. Transhumanisation of ableism where the concept and target group of ableism is now extended to the techno poor disabled
8. The changing role of the disability rights activist, who should be concerned with ableism in the traditional and the transhumanised sense and who should be an activist for everyone mistreated because of perceived or real lack of "abilities," whether traditionally disabled or techno poor disabled.
9. The needed change in mandate of the academic field of disability studies, which itself is concerned with the social situation of the traditional disabled people and which should be replaced by the field of ability studies which would look at the culture of ableism and the mistreatment of people due to ableism in general in its traditional and in its transhumanized sense.
10. Assurance of ability security. One of the issues we see with disabled people is that they lack ability security. With enhancement technologies and the appearance of the techno poor disabled we see more people who do not have a livelihood due to a set of abilities which are seen as deficient (i.e. if one does not enhanced ones body abilities with new products). This process has to be reversed. Ability security has to be ensured.
11. Assurance of self-identity security. With the increases dynamic of medicalisation and transhumanisation of medicalisation(*32*), we see an increase in others defining a person in a negative way which the targeted person accepts subconsciously or without choice (*117*). This dynamic has to be reversed. People should have self-identity security and the right to determine their self-identity independent of outside influences.

From the beginning, this discussion must actively involve disabled persons and other marginalized groups. Their assessment of what they need would inform the development of the research framework and the nature of the research questions. Several core sets of questions would likely emerge. These include questions focused on the following:

1. Identifying the nature of the problem. Questions might include: Is more health gained by using NBICS to fix a person with a certain characteristic or by fixing the societal parameters? Taking into account the societal realities of disabled persons, are medical and NBICS fixes affordable, feasible, and the most efficient use of resources? Do societal solutions better serve the persons in question? Do they lead to improved well-being, broader health equity and better use of limited societal resources and research dollars?
2. Probing for biases in existing policy, research and measurement instruments, and pointing to ways for removal of the biases. For example, undertaking research to determine the extent to which many already medicalised characteristics are in fact conditions in need of medical NBICS interventions or whether they simply reflect

intolerance of diversity and the subsequent pathologisation of persons different from the norm. Research would need to explore who gains and who loses when these biases are left unchecked.

3. Identifying the social determinants and co-requisites for social health of disabled people and the role NBICS can play in improving the determinants related outcome.
4. Monitoring shifts in the understanding of health and disease following advances in science and technology (cf. transhumanist/enhancement model) and identifying and monitoring shifts in health research resource flows.
5. Measuring the impact of new technologies on the medical and social health of disabled persons and other marginalized groups.
6. Monitoring and evaluating the governance of the entire research process, subsequent technological developments and the extent to which disabled persons and their values have informed them. Questions would probe for biases in the governance, monitoring and evaluation processes. They would identify ways to ensure that disabled people and other marginalized groups play an active role in the development and applications of research agendas and new technologies; in defining science and technology and health research questions; and in the decision making regarding health, science and technology and health research priorities. Underpinning this work would be an ethical framework established to conduct critical analysis and evaluation of emerging technologies and to involve disabled people and other marginalized groups to ensure that their rights are protected.

APPENDIX: LIST OF DISABLED PEOPLE GROUPS:

Listed below are primarily disability groups and groups working on poverty among disabled people; which are involved with disabled people in low-income countries; and/or which work on development issues. In addition to this list, one might also approach groups for "patients" who will be affected by nanomedicine and other nanotechnology products as well as groups that work only within their own country.

DISABILITY AND POVERTY

Asian Development Bank
http://www.adb.org/SocialProtection/disability.asp

Since ADB changed its overarching goal to poverty reduction in 1999, a significant amount of regional and country-based activities on disability has been developed. For instance, disability projects, such as ADB's Expanding Employment Opportunities for Poor Disabled Persons, implemented in the three largest cities of Mongolia.
In late 1999, the first ADB Workshop on Disability, held in Manila, concluded with two main recommendations:

1. Strengthening ADB's capacity to address the disability dimension in its operations
Strengthening developing member countries' capacity to mainstream disability
To achieve these recommendations, the ADB approved a regional study to explore disability issues in the region. Provincial and National workshops have been developed in Cambodia, India, Philippines and Sri Lanka - over 1000 persons with disabilities, their families, disability experts and local disability NGOs participated in the consultations.

2. On October 2002, high-level representatives from governments, regional development agencies, international DPOs and people with disabilities were invited to Manila to speak for themselves at ADB's Disability and Development Workshop.

Action on Disability and Development (ADD) http://www.add.org.uk/index_main.html

ADD was set up in 1985. ADD is the only British-based development agency working exclusively with groups of disabled people in Africa and Asia on development and human rights. http://www.dfid.gov.uk/pubs/files/add-ppa.pdf

The Department for International Development (DFID) (http://www.dfid.gov.uk/) is one of their funders.

ADD has a vision of a world where all disabled people are able to participate as fully as they choose at every level of society. To achieve this they work in partnership with networks of disabled people in some of the poorest communities in the world, to help them to campaign for the rightful inclusion of disabled adults and children in society.

ADD is one of the few British-based organisations supporting rights-based development work exclusively with groups of disabled people in Africa and Asia. ADD works in 12 countries of Africa and Asia. There are staffed programmes in Bangladesh, Cambodia, Sudan, Uganda, Tanzania, Zambia, Ghana and Francophone West Africa (Mali, Burkina Faso and Cote D'Ivoire). They also work directly with partner organisations in India and Zimbabwe.

The Disability African Regional Consultative Conference (ARCC)
List of participants
http://www.disability.dk/images/docpics/1055848988_Final_ARCC_Report_-_List_of_Delegates.doc
http://www.disability.dk/images/docpics/1055848944_Final_ARCC_Report_-_Main_Report.doc
http://www.disability.dk/images/docpics/1055848969_Final_ARCC_Report_-_Appendix_Section.doc

Danish Council of Organisations of Disabled People
http://www.disability.dk

- The website contains information on disability in developing countries to support NGOs, governments and others working in the field. The site is build as a dynamic library where the newest documents and information are added. http://www.disability.dk/site/index.php?section_id=1
- The countries they are involved in: Denmark, Ghana, India, Kosovo, Malaw, Nepal, Nicaragua, Philippines, South Africa, Uganda, Vietnam, and Zimbabwe.
- Many DSI member organizations support their sister organizations in the Third World. Normally, they support organizational and policy development, which means improving democratic, organizational structures, educating representatives of disability organizations and developing negotiation structures between authorities and disability organizations.
- The web site is edited by DSI and its NGO-partners. http://www.handicap.dk /eng/ index.htm

Dutch Coalition on Disability and Development
A partial list of participants in DCDD's global network:
DCDD Advisory Council: DCDD has an international advisory council. Its members can be found by clicking here.

Bangladesh:
- Jesh Foundation Bangladesh - Enam Hoque, chairperson. Contact via enam@planet.net.au, website www.jeshfoundation.org
- Paribartan - Abdur Razzak Razu. Contact via amhaque@bttb.net.bd

Bulgaria: Center for Independent Living - Kapka Panayotova, director. Contact via kapkap@mail.orbitel.bg.

Cuba: Ecumenical Disability Advocates Network (EDAN) - Noel Fernandez Collot, Latin American co-ordinator. Contact via fernolla@enet.cu.

Cameroon: Club des Jeunes Aveugles Réhabilités du Cameroun (CJARC) - Coco Bertin Mowa. Contact via coco_bertin@yahoo.fr

Ghana: Centre for Peace & Sustainable Democratic Culture - Abraham Adu Berinyuu. Contact via menvolima@yahoo.com.

Guinea, Republic of: West African Federation Disabled Persons (WAFOD) - Alpha Boubacar Diop, president. Contact via alphabdiop@yahoo.com.

India: READS, Rural Educational Awareness Development Society - Ms. K.A. Amali. Contact via reads_j@yahoo.com

India: Relief Organisation for Handicapped - P.G. Sundari. Contact via roh_hdp@yahoo.co.in

Kenya:
- Ecumenical Disability Advocates Network (EDAN) - Samuel Kabue, co-ordinator. Contact via skabue@edan.or.ke.
- Kenya Deaf Welfare Society - Evanson N. Karanja. Contact via undeaf@yahoo.com.
- Kenya Disabled Action Network - Fredrick Ouko, co-ordinator. Contact via kenyadisabled@hotmail.com.
- Kenya Disabled Development Society - William S. Makori, chairperson. Contact via bodo@avu.org, website www.interconnection.org/kdds

Mozambique: ACAMO (Associacao dos Cegos e Ambliopes de Mocambique) - Fransisco José Tembo. Contact via seppinen@teledata.mz

Nicaragua: Asociación Los Pipitos - Daysi Moncada, Directora Relaciones Internacionales. Contact via rrii@lospipitos.org, website www.lospipitos.org

Nigeria: J
- Joint National Association of Disabled Persons - Godian C. Amadi, secretary general. Contact via gochiwen@yahoo.com.
  Monatan Disabled Community - Christopher Amedola Fawole, founder/co-ordinator. Contact via monatandisabledcommunity@yahoo.com.

Sierra Leone: Sierra Leone union of Polio Persons (SLUPP) - Harouna Samura, PR officer. Contact via unionofpolio@yahoo.com.

Sri Lanka: Central council of disabled persons (CCODP) - R.S. Marasinghe, chairperson. Contact via ccouncil@sltnet.lk, website www.ccodp.org -

Tanzania: Amani centre for persons with mental disabilities - Josephine Bakhita, director. Contact via amani_centre@yahoo.com.

Uganda:
- NUDIPU - Alex Ndeezi, chairperson and MP. Contact via nudipu@starcom.co.ug
- Sheema women and disabled people association - Apollo Leeman. Contact via apolloleeman@yahoo.com
- People With Disabilities Uganda - Richard Mugisha. Contact via pwd@imul.com, website www.pwd-u.org

Zambia: Znaph Chikankata - Bosswell Mboozi. Contact via znaph@zamtel.zm

Zimbabwe: Southern African Federation of the Disabled (SAFOD) - Alexander Phiri, chairperson. Contact via safod@telconet.co.za.

INTERNATIONAL NON-GOVERNMENTAL ORGANISATIONS (NGO'S)

ABILIS Foundation: http://www.abilis.fi/indexenglish.htm
Development fund, founded by Finnish disabled people in 1998, gives financial support to organisations of disabled people in the South.

Chronic Poverty Centre (UK)
Working with disabled people for positive change Action on Disability and Development
Http://www.chronicpoverty.org/cprcaboutCPR.htm http://www.chronicpoverty.org/cp4.htm

Disability and Development Co-operation: *www.bezev.de*
Site of the German NGO Netzwerk Behinderung und Dritte Welt

Disability Awareness in Action. http://www.daa.org.uk/index.htm
The international disability & human rights network

The Disability Knowledge and Research (KAR) Programme
http://www.disabilitykar.net/
The programme is managed in partnership by the Overseas Development Group at the University of East Anglia and Healthlink Worldwide. Part of the UK Department for International Development's broader programme to eliminate poverty in poor countries.

Aims to: Generate research on disability issues to influence policy and practice; Improve access to knowledge and information; Promote discussion between disabled people, service providers, researchers, and policy makers; Develop and support sustainable technologies to combat the effects of disability

Disability Poverty & Development ROUNDTABLE DISCUSSIONS to explore the links between poverty and mainstreaming disability in development. Hosted by FEDOMA in Malawi, India and Cambodia November 2 -4 2004, the event focuses on disability poverty and the Millennium Development Goals.

http://www.disabilitykar.net/pdfs/mapping_report_web1.pdf
Poverty, disability and impairment in the developing world

Summary of perspectives on disability poverty and technology (see below). This is a report from the first KaR Disability programme

Perspectives on Disability Poverty and Technology
This report was commissioned for the first Knowledge and Research Programme on Disability and Healthcare Technology 2000-2003 (KaR1). Read the Perspectives on Disability Poverty and Technology report

Program for Disability Research at Rutgers University
http://www.disabilityworld.org/01-03_04/news/africa.shtml
http://www.disabilityresearch.rutgers.edu/sophie.htm

Disabled People International (DPI): *www.dpi.org*
Network of national organizations or assemblies of disabled people

EC Guidance Note: *via www.dcdd.nl?1698*
European Commission guidance note on how to address disability issues effectively within development cooperation

Ecumenical Disability Advocates Network (EDAN): *via www.wcc-coe.org*

European Disability Forum (EDF): *www.edf-feph.org/*
European umbrella organisation representing more than 37 million disabled people in

Europe

Enabling Education Network (EENET) *www.eenet.org.uk*

EP Disability Intergroup: *www.edf-feph.org/apdg*
A cross-party group of European Parliamentarians from each of the 15 EU member states supporting the rights of disabled people

Healthlink Worldwide
Works to improve the health and well-being of disadvantaged and vulnerable communities in developing countries, by working in partnership to strengthen the local provision, use and impact of health communication and to support advocacy initiatives to increase participation and inclusion.

"Whose voice is being heard?" Read about Healthlink Worldwide's contribution to a recent IDDC/World Bank seminar on collaborating to promote inclusive development.

Health Wrights
HealthWrights is a non-profit organization committed to advancing the health, basic rights, social equality, and self-determination of disadvantaged persons and groups. We believe that health for all people is only possible in a global society where the guiding principles are sharing, mutual assistance, and respect for cultural and individual differences. http://www.healthwrights.org/

ICEVI: *www.icevi.org/*
International Council for Education of People with Visual Impairment

Inclusion International: *www.inclusion-international.org/*
Global federation of family-based organizations for people with intellectual disabilities

Independent Living: *www.independentliving.org/*
Independent Living Institute: develops consumer-driven policies for self-determination, self-respect and dignity

Independent Living Centre Sweden
http://www.independentliving.org/donet/index.html
http://www.cdp-hrc.uottawa.ca/links/discriminationint_e.html

International Disability Alliance (IDA): *www.internationaldisabilityalliance.org*
International platform of international disabled people's organisations

International Disability and Development Consortium (IDDC)
www.iddc.org.uk
IDDC members: ADD, AIFO, BasicNeeds, CBM, DSI, DCDD, FIDIDA, Handicap International, Healthlink Worldwide, OVCI, Leonard Cheshire International, NAD, PHOS, Save the Children UK, SHIA

Ministerie van Buitenlandse Zaken, Ontwikkelingssamenwerking: *www.minbuza.nl*
(Website van het Directoraat Generaal Internationale Samenwerking)/Dutch

Mobility International USA: *www.miusa.org*

Motivation: *www.motivation.org.uk/*
Improving quality of life of wheelchair users worldwide

People's Health Movement: *phmovement.org/*
Aims to draw on and support people's movements to build solutions to health problems

PHOS: *www.phos.be*
Site of the Belgian NGO PHOS: Platform Handicap and Development Cooperation

Rehabilitation International (RI): *www.rehab-international.org/*
Worldwide network of people with disabilities, service providers and government agencies

UNESCO - Inclusive Education: *www.unseco.org*
UNESCO webpage on Inclusive Education

United Nations' Enable: *www.un.org/esa/socdev/enable*
UN's website on equality and full participation

WHO Disability and Rehabilitation: *www.who.int/ncd/disability*
WHO - Disability and Rehabilitation Dept. (DAR)

World Bank Disability Unit *www.worldbank.org/disability*
Worldbank site on disability: including persons with disabilities
http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:20245996~pagePK:148956~piPK:216618~theSitePK:282699,00.html

World Blind Union: *www.worldblindunion.org*
Entitled to speak on behalf of blind and partially sighted persons of the world

World Federation of the Deaf: *www.wfdnews.org*
Comprising national associations of deaf people worldwide

The World Federation of the Deafblind: *www.wfdb.org/*
The World Federation of the Deafblind

World Network of Users and Survivors of Psychiatry (WNUSP): *www.wnusp.org*

Literature:
"Poverty and Disability A Survey of the Literature"
http://siteresources.worldbank.org/DISABILITY/Resources/Poverty/Poverty_and_Disability_A_Survey_of_the_Literature.pdf

"Disability, Equality, and Human Rights: A Training Manual for Development and Humanitarian Organisations" http://www.oxfam.org.uk/what_we_do/resources/diseqhr.htm

"All things being equal: perspectives on disability and development
World Vision, 2001"
http://www.worldvision.org.uk/resources/disabilitypaper.pdf This resource calls for action by policy-makers, planners and managers to make development programmes more inclusive. It reports on the barriers put up by communities as identified by disabled people that lead to their social exclusion.

"Viewpoint: Disability--the Hidden Side of African Poverty." Sophie Mitra. *Disability World* (22). 2004.

Journal:
International Journal of Disability, Development and Education. Christa van Kraayenoord, ed., The University of Queensland, Australia.
http://www.tandf.co.uk/journals/titles/1034912x.asp

POVERTY IN GENERAL

Development Gateway Foundation
http://home.developmentgateway.org/
An independent not-for-profit organization conceived by World Bank President James Wolfensohn and initially developed in the World Bank in July 2001. The Development Gateway Foundation is an enabler of development. We help improve people's lives in developing countries by building partnerships and information systems that provide access to knowledge for development. We exploit powerful and affordable information and communication technologies (ICT) that were previously unavailable to: Increase knowledge sharing; Enhance development effectiveness; Improve public sector transparency; and Build local capacity to empower communities.
Author's note: It is interesting that they hardly cover disability and disabled people.

Caledon Institute of Social Policy
The Caledon Institute is a social policy think tank established in 1992, a private, non-profit organization with charitable status. It is supported primarily by the Maytree Foundation, located in Toronto. Caledon is an independent and critical voice that does not depend on government funding and is not affiliated with any political party. Caledon welcomes charitable donations from individuals and organizations and occasionally undertakes contract projects for governments and nongovernmental organizations on the basis that such work advances Caledon's research agenda, but does not define it.
http://www.caledoninst.org/ http://www.caledoninst.org/Publications/PDF/378ENG.pdf

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