

Nr. 213 | December 2005-12-27

Knowledge of the Brain Must be Used with Care

Large interests at stake in brain research that moves the boundaries of normality

A panel of citizens wants knowledge of the brain to include the diseased as well as the healthy brain >

A fear that significant areas of research are neglected >

The risk of pathologization >

On an almost daily basis we are presented with new knowledge of the brain. This is a knowledge that instils renewed hope in many who suffers from serious medical conditions, but it is also a knowledge that challenges a number of basic social values. Thirteen citizens have considered some of the dilemmas raised by the latest advances in brain research, and they point out that the use of new knowledge of the brain must not be restricted to the treatment of diseases – it also holds a great potential for an increased understanding of learning and development that may be highly useful, e.g. in the school system. Citizens are worried about the massive influence of the pharmaceutical industry and afraid that significant areas of research are neglected, because they are of no interest to the pharmaceutical industry. Furthermore, citizens fear an increased pathologization and a change in our understanding of what it means to be normal. Meanwhile, experts warn us not to believe that our knowledge of the brain is complete, just because we can now see pictures of it. Brain research creates controversial knowledge that necessitates an open debate.

This newsletter is a report from a consensus conference on the question: How is the new knowledge of the human brain to be used. The conference was held by The Danish Board of Technology at Christiansborg Castle November 4th – 7th 2005.

We are headed towards a society in which brain medicine is prescribed for healthy children and adults. This warning was issued May 2004 by an international group of leading brain scientists, including Nobel Prize winner Eric Kandel of Columbia University. They emphasized among other things that as many as sixteen percent of the pupils and students in several American high schools and universities are known to take memory enhancing drugs by prescription as a means to improve their performance in school. The scientists

compare this to doping in the world of sports and warn that the increased importance attributed to 'brainpower' in the knowledge society may soon force all citizens to make use of 'brain-doping'. Other internationally acclaimed scientists, such as Professor Steven Rose of The Open University in England, warn that there is a rising tendency to medicate social problems rather than diseases. In England, according to Professor Rose, the number of prescriptions of Ritalin for children suffering from ADHD/DAMP (attention-

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deficit/hyperactive disorder) has increased from 2,000 in 1990 to 160,000 today – a tendency that is paralleled in other European countries. In his view, these numbers do not signify an increase in brain disorders among children, but rather that new psychoactive drugs have made it cheaper and easier than ever before to control the behaviour of children with serious social problems. In general, Rose finds it alarming that society increasingly turns to medicine as the proper way to solve a problem.

Danish and European Citizens to Assess Brain Research

Within the last few years brain technology and genetic engineering have begun to equip us with very strong tools for the treatment and diagnosing of serious neuro-related disorders. But as indicated in the warnings mentioned above, this new knowledge is also connected to a number of serious dilemmas. This knowledge places new methods of treatment at our disposal, but it also pokes at big issues such as the definition of normal vs. abnormal, of healthy vs. ill and even issues as basic as the definition of human life. The brain is the place where experiences are stored and memories are retrieved, the place where ideas arise and thoughts are born, where decisions are made and pleasure, pain, grief, joy etc. is felt. Hence any increase in our understanding of the brain is bound to trigger moral, ethical, legal and socio-economic questions of a very fundamental nature. Questions too important to be handled by the experts on their own, questions that must be debated by the population at large.

The Consensus Conference Method

The consensus conference takes place as a dialogue between a group of experts and a panel of citizens that is broadly representative of the Danish population and consists of people without any professional connection to the subject. The role of the experts is to inform the panel of citizens about a given technology and its consequences. The role of the citizens is to pose questions to the experts and to put together a final statement that contains a clarification of and an opinion about the subject. On the third day of the conference this final statement is presented to politicians, the media and the audience. This kind of conference seeks to bridge the gap between citizens, experts and politicians, while also contributing to an open, public and democratic debate.

For the first time ever in the history of Europe, therefore, 125 ordinary Europeans have been asked to join the discussion and express their opinion on how this new knowledge of the human brain is to be used (see box). *Meeting of Minds* is a large-scale pilot project that involves citizens in the decision-making on a matter so complex that only scientists with a

lifetime of experience in the field are capable of fully understanding the background. These scientists, then, for their part, have expressed the opinion that although they are the ones who produce new knowledge, they are not supposed to decide on their own how to use this knowledge. Today, high-tech societies are faced with a growing democratic dilemma. In 2004 the big ethical and political issues raised by the new knowledge of the brain caused a group of German brain scientists to write a statement in which they call for a comprehensive debate on brain research and its findings.

European Citizens in a Dialogue on Brain Research

The consensus conference of the Danish Board of Technology is part of the Meeting of Minds project in which institutes of technology assessment, science museums and universities from nine European countries have joined efforts to carry out a European pilot project on the involvement of citizens in decision making processes. The project includes Germany, France, Italy, England, Holland, Hungary, Greece, Belgium and Denmark.

Read more about the initiative here:
www.meetingmindseurope.org

At this website you will also find the conclusions of the citizens in the other countries, just as you will find an English translation of the statement by the German brain researchers

The Danish Board of Technology and the Danish panel of citizens are a part of the Meeting of Minds project. November 4th – 7th a consensus conference was held at which the Danish panel of citizens, helped by a number of experts, tried to shed light on the dilemmas of brain research. This newsletter covers the conclusions that the panel of citizens arrived at. The panel will bring these conclusions to the European citizens' convent to be held in Brussels January 20th – 23rd 2006. At this event 125 European citizens are to agree on what kind of frameworks and guidelines they want to recommend European and national politicians, researchers, the industry and other interested parties to implement in brain research and in the use of our knowledge of the brain.

The citizens view brain research as a diverse and interdisciplinary field and they are critical towards relying on medical research alone. They feel that society has an interest in employing new knowledge of the brain also in pedagogy, education, prevention and rehab programs and in the use of creative resources etc. In the elementary schools, for example, one could allow for the fact that boys and girls do not grow mature at the same pace and that in the early years of school boys are not capa-

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ble of concentrating for as long at a time as the girls. Correspondingly, it should be noted that our brains develop all through our lives and that we are therefore never too old to learn something new.

Psychoactive Drugs Help the Mentally Ill

Following the conclusions drawn at the conference, today's focus on the medical aspect of the brain is conditioned by the historical situation in which the advent of psychoactive drugs proved to have an enormous impact on the treatment of diseases such as schizophrenia and depression by completely shifting the emphasis from dialogue to medicine.

The Recommendations of the Danish Panel of Citizens

Under the headline "How are we to use the new knowledge of the human brain" the panel of citizens discussed a number of topics: normality vs. diversity, the pressure from economic interests, free choice, equal opportunity, public information, regulation and control. For each topic the panel has described the most significant problems and assessed the knowledge passed on to the panel by the experts. On that basis the panel has prepared a total of 28 recommendations concerning the use of the new knowledge of the brain. In relation to the topic of normality, for example, they point out that the new knowledge of the brain makes it much easier to understand, diagnose and treat diseases, but that this very knowledge may also lead to unnecessary pathologization. Therefore, the panel of citizens recommends that brain research continues to be an interdisciplinary endeavour that involves the approaches of the humanities and social studies. Furthermore, a part of the funds allocated to research in brain diseases should be used to identify the interplay between neurological causes and other causes to be found in the social and cultural environment. For this reason, the panel also calls for an improved general view of what kind of brain research is actually carried out. In their opinion, politicians and health authorities should focus on the prevention of brain-related diseases.

Read the entire final statement here:

http://www.tekno.dk/pdf/projekter/p05/_hjerneforskning_slutdokument.pdf

The Danish project on brain research with podcast from the consensus conference:

<http://www.tekno.dk/hjerneforskning>

According to Claus Bræstrup, President and CEO of H. Lundbeck, Ltd., psychoactive drugs and the pharmaceutical industry have been extremely successful in helping patients with mental illnesses.

"Fifty years ago, people suffering from depression were merely kept in mental asylums where they did nothing but sit around", he said. "Today we are able to actually help in

almost 80 percent of these cases by way of medicine and therapy."

Supported by medicine, people suffering from schizophrenia are able to live a relatively normal life, just as there is at least some relief to be found for diseases such as Alzheimer's disease and Parkinson's disease.

It has become quite clear, however, that the brain can be affected by talk therapy as well as by medicine. Therefore, today, most agree that the optimal treatment for diseases such as depression is a combination of medicine and psychotherapy.

Even though psychoactive drugs have been highly successful, there is still no cure for the four diseases mentioned above. Likewise, it remains an open question how these diseases arise and why the medicine works.

The Brain Changes Every Day

Naturally, great progress has been made in our understanding of the human brain. One of the most significant discoveries has been that the brain is actually characterized by a pronounced readiness to change.

While it was previously assumed that the brain was locked in a fully developed form by the onset of adulthood, it is now known that the brain changes every single day.

"We will all have a different brain tonight than the one we brought here today", explained Jesper Mogensen of The University of Copenhagen at the consensus conference.

What he meant was that there is a continual build-up of new connections between the cerebral nerve cells, whereas old connections disappear when they are no longer used. This means that experiences will change the brain physically, that we may continue to learn new things all through our lives and, not least, that brain-injured may regain a part of the abilities they have lost by training other parts of the brain to take over the damaged functions. Modern brain research is largely driven ahead by increasingly advanced scanners that serve to map where, exactly, the different brain processes unfold and develop. However, when it comes to the question of how a memory, an emotion or a complex mental illness arises, researchers are still far from capable of providing any real answers. Or, as Professor Albert Gjedde, Aarhus University Hospital, dryly remarked: "We know almost nothing about how the brain works."

This may seem quite disappointing and it is certainly completely at odds with the stories told by the media who frequently announce that scientist have now found the genetic code behind falling in love, intelligence etc. In addition to the influence of the pharmaceutical industry, it is exactly this general impression, this belief, that scientists have an almost complete knowledge of how the brain works and that all kinds of things can be achieved with brain medicine, that creates the basis for a distortion of research.

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Citizens Worried that Research is Industrially Controlled

The citizens in the panel are pleased, of course, that there is an ongoing research in new methods of treatment. They have no doubt that the cooperation between Danish researchers and the pharmaceutical industry is working very well as far as medical research is concerned. They are generally worried, however, that it is actually the pharmaceutical industry who controls what areas are made the subject of research. This industry has no interest in a mapping of the social and cultural circumstances that may lead to a neurological effect. On the contrary, the pharmaceutical industry has an interest in making sure that diseases of the brain are treated by medicine. Therefore, the panel of citizens recommends that a certain part of public grants for brain research is always allocated exclusively to research in prevention and in other possible causal relations.

They also recommend that politicians agree to secure continued research in the smaller diseases that the pharmaceutical industry may not find profitable. They recommend that it is guaranteed that there will continue to be carried out research and training in psychotherapy and other treatments such as electrotherapy that are not based on medicine, and that prevention is placed higher on the agenda for politicians and health authorities.

It is also highly important that current procedures for the approval of new medicine are not relaxed and, in the long term, that financially strong parties are prevented from influencing politicians and decision makers to ease the rules.

Shifting the Boundaries of the Normal

In close connection to the treatment aspect, the panel of citizens finds a discussion of normality to be essential. It is feared that the new knowledge of the brain may lead to a narrow view of human nature. The citizens do not want a designer society without room for people who are a little deviant. What is sick, what is healthy, what is sane and sound, what is unsound and deranged, what is normal and what is abnormal? Certain groups of people who are deaf by birth, for example, feel discriminated when they are offered an ear-implant – an imperfect technology that does, however, make them capable of hearing by way of an electrode inserted the brain. According to this minority, technology changes them from persons to patients. They risk not being able to share sign language and deaf culture with their deaf children, if these children have the ear-implant at an early age and become hearing. They risk being alienated from their own children. Another example could be hyperactive children diagnosed to suffer from ADHD/DAMP. The risk here is that the boundaries will start to slip, if we begin to is-

sue medicine to children that previously would just have been considered very lively. Perhaps, what these children actually respond to is the social circumstances of their parents or the various demands to their performance in school – all of which is really the result of an increasingly demanding society. This discussion is also relevant to an issue such as depression: When social demands are combined with the possibility of antidepressants, the outcome may be that it becomes less acceptable to be sad, to have an introverted character or simply to not always beam of joy.

The panel of citizens is afraid that new knowledge and enhanced technological possibilities will put us at risk of creating a society in which things that we consider to be normal at present will cease to be acceptable. They recommend that an effort is made to distinguish between what must be considered a variant of the normal and what is truly a disease. According to the panel, it is of paramount importance that it is not left to brain researchers alone to assess the societal consequences of the new knowledge as far as normality, human nature, morals and the view of illness is concerned. They feel that it is necessary to involve other researchers such as philosophers and experts in ethics as well as politicians and citizens in general.

Inherent in the increased knowledge of the human brain and the advances in genetic engineering is the possibility of screening for brain diseases with hereditary elements such as schizophrenia, autism, Alzheimer's disease and Parkinson's disease. The panel of citizens is of the opinion that we must be extremely careful with screenings and early diagnosis, because the outcome of such measures are highly dependent on the norms and interests in society and because they may lead to an unnecessary pathologization. They feel that it should be possible for people who are genetically predisposed to a specific disease to be examined and diagnosed. But screenings of the entire population or parts thereof should only be carried out for diseases that are life threatening *and* curable. Screenings and tests must never be carried out for any other reason, as for example for insurance reasons or by demand of an employer. All counselling in relation to tests and early diagnosis must contain information on whether treatment and cure is at all possible.

Knowledge Must be Sorted and Made Socially Robust

One of the biggest problems is communication about research. "The important thing today is not how to handle what we know, but how to handle what we do not yet know", as Maja Horst, Assistant Professor at Copenhagen Business School, pointed out at the conference. The discussions of scientific results are open to the public. The time when debates on

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science and research were confined to the ivory towers of the universities is long gone. "Today, research is something that takes place in a complicated network with many interested parties, all of whom feel entitled to interpret the results", Maja Horst explained. "In addition, only very few decisions are made on a rational basis alone."

The interested parties are for instance researchers, industry, patients' associations, politicians, foundations, health authorities and administrators of public funds. This complexity means that an overwhelming amount of information is available to the citizens. If it was previously hard to obtain sufficient information, the challenge today is rather to sort this information – to find substantial and reliable information".

Conversely, the various interested parties are charged with the task of producing what Maja Horst calls 'socially robust knowledge', i.e. a knowledge that is accepted on several levels of society, not just as being true, but also as being legitimate and socially correct, a knowledge that does not cause more problems than it solves.

Within the field of brain research it is especially hard to find clear information, because, unlike a fractured leg or tuberculosis, so many brain diseases, including depression, autism and schizophrenia, do not have a clear diagnosis. They are rather characterized by a lack of hard-and-fast boundaries between severe and mild forms. Furthermore, there is often overlapping traits between e.g. cases of retarded development and autism. Also, diagnosis is based on a mere list of characteristic traits and only guaranteed by the experience of the doctor.

Such uncertainties are also reflected in the current debate on the reason why several diseases like ADHD/DAMP, autism and depression is rapidly growing in the western world. Some experts are of the opinion that this rising tendency is a reflection of the fact that more refined diagnostics have made it easier for us to detect the disease (as in the case of autism) or that we have simply begun to acknowledge the real scope of the problem (as in the case of depression). Others point out that the almost epidemic proportions of this rise can only be explained by outside factors, e.g. that modern society is extremely demanding which causes many cases of depression. These are reasons that call for entirely different solutions and thus make it very difficult for the family of the afflicted person to decide which information to rely on.

All this is rendered even more complicated by the conflicts of interest between various parties. The system, the patient and the family may all have an interest, for example, in having a particular problem recognised as a medical problem, because this is initially less costly than, say, taking on issues of a social nature. For the family, one diagnosis may be prefer-

able to another in that it will prompt the system to offer a treatment plan. Also, a medical explanation may be a relief to the family, because it will put the 'blame' on biology rather than social circumstances.

Avoid the "Google Syndrome"

In general, then, it is very difficult to choose the best treatment. Diseases of the brain have a profound effect on patients as well as their families, and the panel of citizens feels that is very important that people are sure to receive reliable and relevant information. Within the field of the brain, counselling and information need to be strengthened substantially. It is also necessary to take steps to ensure that there continues to be a high level of education in all the professional areas of the treatment system. The panel of citizens are in favour of having the researchers themselves inform the public of their results so as to prevent the media and "the story" from stealing the picture and dictating the agenda. The panel wants to avoid the "Google Syndrome", i.e. the tendency that citizens are able to find all kinds of information on the Internet without, however, really having a chance of assessing its merits. Therefore, the panel suggests that reliable information of this kind is made available on a website. This website must cover brain research in a broad sense and be easy to understand, user-friendly, reasoned and impartial. Controversial knowledge is extremely difficult to disseminate in a proper way. It is important, therefore, that there is ample room for discussion and that it is not attempted to propagate some narrow 'truth'.

Sources and Links

* Warning from international group of brain scientists: Nature Reviews, Neuroscience, vol. 5, pp. 421-426, 2004.

* Neurologist Steven Rose:

<http://www.open.ac.uk/science/biosci/research>

* Statement by German brain scientists in the journal Gehirn & Geist, November 2004:

http://www.gehirnundgeist.de/blatt/detgg_manifest

The Panel of Citizens

Anders Boffy Johansen, aged 24, night porter, Ballerup.

Birgit Gunnild Skov, aged 65, retired correspondence clerk, Værløse.

Carsten Grubb, aged 62, civil engineer, Farum.

Gerda Hempel, aged 47, director of ArtLab, Nødebo.

Hanne Fynbo, aged 59, accounts clerk working from home, Ærø.

Kirsten Margrethe Rajakumar, aged 56, computer programmer, Dragør.

Lene Vestergaard, aged 47, psychiatric care worker, Viborg.

Maria Sveigaard, aged 30, social worker, Tureby.

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Fra rådet til tinget

Newsletter from The Danish Board of Technology to the Danish Parliament

Mogens Høy Seegert, aged 54, plumber, Malling.

Per Veber, aged 36, schoolteacher, Aarup.

Sarah Sehinde Bugyei, aged 20, student, Copenhagen.

Søren Petersen, aged 45, production co-ordinator, Rønne.

Villy William Madsen, aged 60, unemployed labourer, Esbjerg.

The Panel of Experts

Albert Gjedde, Professor, PET Centre, Aarhus University Hospital.

Andreas Roepstorff, Associate Professor, CFIN and Department of Anthropology, The University of Aarhus.

Birgitte Bo Andersen, Consultant Doctor, The Memory Clinic at The National Danish Hospital.

Christian Gerlach, Director of Research at Learning Lab Denmark, DPU.

Claus Bræstrup, President and CEO of H. Lundbeck, Ltd.

Gitte Moos Knudsen, Professor of Neurology, The National Danish Hospital and The University of Copenhagen.

Helge Kjersem, Unit Administrator, Herlev Hospital.

Helle Bødker Madsen, Associate Professor, School of Law, The University of Aarhus.

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Maja Horst, Assistant Professor, Department of Management, Politics and Philosophy, CBS.

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Tine Palmskov, Chairman of the ADHD Society in Frederiksborg County.

A planning group is also attached to the project:

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In addition to these: **Albert Gjedde, Andreas Roepstorff, Birgitte Bo Andersen and Christian Gerlach** (All mentioned in the above).

and edited by Ida Leisner. This issue is written by freelance science journalist Rasmus Kragh Jakobsen. **Please address any questions you might have concerning this newsletter to Project Manager Ida-Elisabeth Andersen, ia@tekno.dk**

The latest five issues of the newsletter:

No. 212: Overweight Children and Malnourished Elderly

No. 211: More Digital Power to the Citizens

No. 210: Pisa – An Eye-Opener and a Creator of Controversy

No. 209: The Need for a Discussion of Digital Rights

No. 208: The Commodities of the World Ride on a Surge of Oil

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