Meeting of minds

The brain: case studies, food for thought, debate

(Version 7 February, 2005)

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Colophon

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This is a joint publication of the Meeting of Minds consortium:
King Baudouin Foundation (Brussels, Belgium)
University of Westminster (London, United Kingdom)
Flemish Institute of Science and Technology (Brussels, Belgium)
Danish Board of Technology (Copenhagen, Denmark)
Cité des Sciences et de l'Industrie (Paris, France)
Stiftung Deutsches Hygiene-Museum (Dresden, Germany)
IDIS-Foundation - Città della Scienza (Naples, Italy)
Rathenau Institute (The Hague, Netherlands)
Science Museum (London, United Kingdom)
University of Debrecen (Hungary)
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xxxx

Layout

IDIS Foundation - Citta della Scienza, xxx department

Printing

[To be filled in by each partner]

ISBN: [*by each partner*]
Legal deposit: [*if necessary*]

This publication is available free of charge:
Online at: www.meetingmindseurope.org
[Other possibilities to be mentioned by each partner; e.g. see below the standard wording by the KBF]
[E-mail: public@kbs-frb.be
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An initiative of the King Baudouin Foundation
with the support of the European Commission

March 2005

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Foreword

This information brochure summarises the key issues and questions in brain science that are of crucial relevance to the people of Europe, both now and in the near future. Important debates on what is possible, what is desirable and how we should be regulating advances are taking place around the world. Advances in brain sciences raise many ethical, legal and social questions, and will affect every European citizen one way or another. It is important, therefore, to start thinking about the societal consequences of brain research and to involve citizens in this process**.** The time has come for the public, researchers and policymakers in Europe to further explore the issues at stake in the field of brain science and to focus on the following key question: 'How are we going to use our new-found knowledge of the brain?'

A European Citizens' Deliberation

Meeting of Minds. European Citizens' Deliberation on Brain Science is a two-year pilot project led by a European panel of 126 citizens. A partner consortium of technology assessment bodies, science museums, academic institutions and public foundations from nine European countries launched this initiative in 2004 with the support of the European Commission.

The initiative will give European citizens a unique opportunity to learn more about the impact of brain research on their daily lives, discuss their questions and ideas with leading European researchers, experts and policymakers, put them in touch with fellow citizens from other European countries and make a personal contribution to a report detailing what the people of Europe believe to be possible and desirable in the area of brain science.

With these objectives, the Meeting of Minds initiative wishes to meet EU calls for greater public involvement in the debate on future research, technological decision-making and governance.

The project consists of three national and two European meetings to be held in 2005 and early 2006. Initially, 126 citizens from across Europe will be invited to explore the issue of brain science. This will lead to the creation of a common framework, setting out those aspects of brain science that need to be examined further and discussed in greater depth. National panels will take these proposals home and continue working on them at two national assessment meetings. Each panel will produce its own conclusions on the desirability and potential of brain science. The second European meeting will take on board the national conclusions and run further with them, producing a European assessment report on brain research issues. The participants will discuss areas of overlap and dissension, the underlying reasons for them and what can be learned. The results of these discussions will be incorporated in a European report to be handed over to high-level European officials and representatives of the European scientific and research community at a public ceremony. One of the aims of this exercise is to create an ongoing dialogue at European level between the general public and policymakers on science-related matters.

Brain Science

Brain diseases are forecast to become a large and growing burden for ageing Europeans. It is predicted that by 2030 about 50 percent of the population will have a brain disease.

But recent advances in brain sciences go far beyond curing disease. They also raise pressing questions about the ethics of enhancing, controlling and scanning our brains. These issues go right to the core of our identity: what it means to be human, and how we can retain our sense of self. Science is giving us ways to boost our intelligence, expand our memories and read our thoughts. But will we be allowed to make up our minds about what we want?

The Aim of this Brochure

This was initially designed as a tool for use by the group of citizens taking part in *A Meeting of Minds. European Citizens' Deliberation on Brain Science*. Six case studies on the brain provide starting points for reflection and discussion on issues that are either relevant now or will be shortly. They offer food for thought and debate.

The brochure seeks to open doors so that the impact of brain research can be explored from various angles. The aim of the exercise is to encourage ordinary people to think, reflect and contemplate – without stumbling over technical and scientific hurdles. The document can also be used as a resource by other interested parties -- NGOs, educators, patient organisations, politicians and other policymakers, etc. – seeking information to facilitate the debate on how to use our new-found knowledge of the brain.

Meeting of Minds wishes to thank writers Peter Raeymaekers, Karin Rondia and Marjan Slob as well as the members of the reading committee, Professor Christine van Broeckhoven, Professor Johan den Boer, Professor Marc Jeannerod, Flavio Keller and Dr Andreas Roepstorff for their excellent work. A special thanks also goes to Dr Anne Beaulieu from the Royal Netherlands Academy of Arts and Science who has provided expertise for the case on brain plasticity. The partners hope that anyone reading this brochure will discover that the 'mind matters'.
This brochure does not seek to take any particular position or to pass judgement. Its only purpose is to provide information and raise awareness so that any interested parties can play an informed role in helping decide on the direction in which our society should evolve.

[Signed by **xxxx**, director (or whatever) of name of your organisation]

Introduction: You and your brain

You see with your brain - though you need your eyes for this. You feel happiness and pain with your brain - even though it is well packaged in a skull that is a half centimetre thick. You hear, smell and taste with your brain. All the information that reaches you via your senses only ‘exists’ for you after your brain has registered it. We think, dream, remember, fantasise, choose and plan with our brain. But also our emotions and feelings only actually ‘exist’ for us when our brain becomes aware of them. In a sense, we *are* our brains. They are the key to what we are.

Recent technical developments have opened the door to rapid progress in better understanding this magnificent, complex and extraordinary brain. It has become possible since the 1990s to perform a scan of a functioning brain. Because such a scan is innocuous, scientists can engage in so-called fundamental research. They can ask healthy human test subjects to think or do something whilst the scanner shows at which spot the brain is active. This allows scientists to look, as it were, into the human brain, simply to know how it in fact works. In addition, growing insight into the functioning of cells, including brain cells, allows scientists to understand better what they ‘see’ on the scans.

To put things into perspective, much has yet to be discovered about the brain. Some parts of the brain are difficult to view with scans. Moreover, it seems that typical human capabilities such as speaking, recalling memories and making calculations do not take place in only one area of the brain, but occur in several places at once. These locations can also vary. It appears that everything in the brain is related: a memory also evokes a feeling that perhaps goes together with a smell. This makes it difficult for scientists to unravel the puzzle. Add to this the fact that individual brains differ as much as human faces do: unmistakably human, but highly individual. Yet a good start has been made in describing the human brain. And perhaps more importantly, there are now promising research-methods available.

Prospects are that our insight into the brain will increase quickly in the years to come. This knowledge will also bring with it possibilities to influence our brain. This is encouraging news. Many human disorders - some estimate as many as thirty percent - can be traced back to problems with the brain: strokes of course, but also Parkinson's disease and Alzheimer's disease, as well as a very broad range of psychiatric and emotional disorders such as schizophrenia and depression that can impose terrible suffering on people. New knowledge of the brain enables doctors to make better diagnoses and scientists and pharmaceutical companies to focus on finding effective and safer treatments.

The most common way of artificially changing the manner in which our brains work is via medication. A simple sleeping pill changes something in the brain. A cigarette as well. Meanwhile, a broad range of pills is available on the market to treat emotional illnesses, sometimes with surprisingly good results. Pills to treat Alzheimer's are being developed.

Medication, however, is not the only way to influence the brain. Brain cells communicate with each other via electrical signals. Scientists are also focusing on this phenomenon. Electric shocks are a crude and almost old-fashioned example of this principle. Today, scientists are developing techniques to treat psychiatric patients from outside of their skull with gentle magnetic waves, while neurosurgeons are able to implant small electrodes in certain areas of the brain to treat unpleasant symptoms.

But we should also not underestimate the healing power of *words*. Scans show that the brain does actually look different after successful psychotherapy. The word of the psychotherapist can ostensibly be as effective as the scalpel of the neurosurgeon.

These developments offer hope to millions of European patients with brain disorders and their families. However, we are human. Which is why we can imagine that these pills, electrodes and words could also be used for other purposes: not to cure people, but to change them.
It is at this point where the major social and ethical questions evoked by the brain sciences arise, because change is not considered an improvement by everyone. Change and progress might be accompanied by ethical concerns and social costs. Perhaps there will be loss of solidarity; we might get in a permanent performance race; or we will be deprived of our free will as in Aldous Huxley's novel 'Brave New World'.
Clearly, there is room for discussion on all these issues. Each culture and each society will need to adopt its own standpoint in this regard. They more or less force us to collectively reflect on and imagine our future as humans.

This brochure profiles a number of people who are faced with a decision: what should they do? Or, what should they think? The stories are fictitious, but they are based on real facts. One concerns a man who knows from a brain examination that he is probably going to develop Alzheimer's. A mother has doubts concerning whether she should allow her son to take medication to treat ADHD (Attention Deficit Hyperactivity Disorder). A young scientist studies the brains of newborns in relation to the first dialogue between mother and child. A judge asks how he can still hold a criminal with a deviant brain pattern responsible for his actions. A man with Tourette syndrome recounts his decision to allow electrodes to be implanted in his head. And a young person who took pills to perform well in exams questions the value of the results obtained.

These stories provide starting points for reflection and discussion on issues that are either relevant now or will shortly be so. They offer food for thought about the eternal, universal question: who are we? How can this organised lump of cells in our head make it possible for us to create works of art, plot and scheme, and build intelligent equipment? Allow us to feel desperate, or at one with the universe? But these stories also trigger the question how we are going to deal with the new information on our brain, both at the personal and at the societal level.

[Keyword: limits of normalcy, medicalisation of daily life, ADHD, depression]

1. ADHD, a child with a disorder?

the story

> *I know: Peter is an active child. He never sits still; he is always doing a thousand things at the same time and doesn't pay attention to what he is doing. He was like that as a pre-schooler and I thought, my lively little boy. He liked school, played with friends, participated in wild games. These days he doesn't like to go to school anymore. He is required to learn to read and write, and may not simply leave his seat when he wants to. He finds this difficult.*
>
> *His teacher says that he has difficulty concentrating and that he disturbs the other children. In the meantime, Peter is receiving extra lessons because he is falling behind. So young! He is only seven years old. Peter is also difficult to control at home. What we say appears to go in one ear and out the other.*
>
> *I always thought that he was simply a boy with a lot of energy and that he would grow out of it. However, the teacher has just recommended that I speak with the family doctor. She thinks that Peter might have ADHD, a brain disorder that inhibits the ability of children to concentrate and causes them to respond to every impulse coming from their surroundings. Peter is indeed active and easily distracted. But a brain disorder? So he really is abnormal?*
>
> *In the meantime I have indeed seen the family doctor and have read quite a bit about ADHD. I don't know what to do. There is medication to treat ADHD, Ritalin, which appears to work pretty well and does not have too many side effects. However, must I administer medicine to my 7-year old son everyday? Won't he become addicted to this drug? And for how long should he take this? His whole life? ADHD does not always go away after puberty. No one knows exactly what the effects of these pills are in the long run. It might even change him fundamentally as a person. The thought of stuffing my child full of pills is a depressing one.*
>
> *On the other hand, things are not going well at school. I understand that the early school years are very important to Peter's future. It seems that children with ADHD often drop out and have problems with social interaction. If medication can prevent Peter from falling by the wayside…*
>
> *Sometimes I think: what if Peter had had a different teacher with whom he got along better? Or, what if the classes had been smaller? Or, what if it was not so important to sit nicely on one's chair in school? Then perhaps others would have considered Peter an endearing, lively little boy. But now he is seen as difficult and I must decide whether I want my child to take this medication.*

the facts

Prescriptions for ADHD-drugs (Attention Deficit Hyperactivity Disorder) are on the increase. More and more children are diagnosed with ADHD, and more attention is being paid to adults with ADHD. More boys than girls (three to five times as many) suffer from the illness.

The neurotransmitter *dopamine* appears to be less effective in people with ADHD, impairing the ability of the different regions of the brain to exchange information. Scientists suspect, for example, that people with ADHD cannot follow the thread of a conversation. When confronted with a new impulse, they are unable to think 'this is for later, now I am busy with the present conversation'. Instead, they respond immediately to the new impulse. This leads to the typically chaotic and impulsive behaviour of people with ADHD. What *precisely* goes wrong in the brain of a person with ADHD, and why, is not yet known.

Medication, of which Ritalin is the best known, increases the concentration of active dopamine. This improves communication between the areas of the brain. People who take it are better able to order the impulses of their surroundings.

the issues

It is not possible to diagnose ADHD with certainty, not even by using brain tests. Thus, ADHD is diagnosed using a rule of thumb. There is a list of 21 symptoms, and a child must have 15 of these symptoms to be officially diagnosed with ADHD. This rule of thumb is based on professional experience but does imply a grey area. What precisely is meant by 'active'? When can we speak of a 'pattern' of impulsiveness?

There are various degrees of ADHD. In its severe form, it is a very serious disorder containing risks of dropping out of school and anti-social behaviour. However, because the use of Ritalin has increased to such a degree, the impression exists that children with a light form of ADHD or even normal children who are simply very active are now taking pills. The vagueness of the diagnosis provides the latitude for this.

Critics point to the social pressure to which children and their parents are exposed. Life is becoming faster and one must perform. If your child has difficulties with this, there is a serious problem. As crazy as it may sound, the label 'ADHD' can offer a solution because it provides recognition, and the opportunity to do something about the problem. Problems encountered by parents in raising their children are thus 'translated' into medical problems, for which, of course, a medical 'solution' is sought – like a pill. The suspicion exists on the part of some that the enormous increase in the number of people with ADHD points in part to the (too) high demands placed by society on parents and children; by *medicalising* the issue of children who do not perform well at school, this consideration disappears from the picture. It means that other possible solutions to the problem of underperforming schoolchildren, like changing the policy of schools, are not seriously considered.

The societal effect of 'choosing' the medical route is perhaps that more children are labelled ADHD than can be scientifically justified. This increases the pressure on other parents. Their child might also occasionally be unable to sit still and probably does not always pay attention in school. Should they do something before he begins to fall behind? The fear exists that we will all end up in a 'pill race'.

DSM and the pharmaceutical industry

ADHD is a syndrome. That is to say: a child with a typical combination of symptoms (of which 'hyperactivity' and 'lack of concentration' are two) is by convention called 'a case of ADHD'. This convention is based on the professional experience of psychiatrists, and written down in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). This manual lists all the 'recognised' psychiatric disorders and most psychiatrists in the western world works with this (American based) handbook. The DSM counted 180 diseases in 1951, 292 in 1987 and the latest version, DSM-IV, presents over 350 categories.

A pharmaceutical company is only allowed to bring a psychiatric drug on the market if it is tested extensively (for safety and efficacy) *and* if it is meant to deal with an affliction mentioned in the DSM. Pharmaceutical companies are commercial enterprises which can only make profits if the drugs they launch are successful, i.e. if many people take the drug. According to some, this leads to a pressure from the industry on the medical and psychiatric professional world to increasingly recognise more syndromes and to allow prescription of the same drug for larger groups of patients.

Depression

Depression is a sustained feeling of misery and passivity. In its severe form depression leads to a state of suffering which totally incapacitates the afflicted person. Prescriptions for depression have risen at least as spectacularly in the last decade as those for ADHD. Like ADHD, depression is a syndrome: there is no simple and definitive test available to diagnose depression, which leaves room for 'severe' and 'very light' cases of depression – and the vast area in between. Similar to ADHD, there is a gender-imbalance, although this time the other way around; about twice as many women receive treatment for depression as man. And, also like ADHD, a disturbance of the balance of a neurotransmitter (serotonin is the prime candidate in this case) correlates with the syndrome. There are differences too. ADHD is typically an affliction of children, depression one of adults – though there are many exceptions to this rule.

The fact that so many people lately have been diagnosed as ‘depressed’, has provoked two types of reactions. Spokesman of the first camp state that this can be seen as an improvement: the disease is simply better recognised. Moreover, modern pharmaceutical treatment (like Prozac and Seroxat) is more effective and has less side-effects, so it makes sense to diagnose depression the way we do. At last something relatively simple can be done about it!

For the other camp, the fact that depression is diagnosed much more often means that people really *are* more often depressed than before. This might be a symptom of an over-demanding society, they fear. A society which leaves little room for sensitive, brooding characters, or for difficult periods in the life of its members. To dull these symptoms by prescribing pills might be a misrecognition of the afflicted people, and might desensitize us as a collective.

The ideal treatment of depressed persons differs according to ones beliefs. Almost nobody contests that pills are benevolent in the case of severe depression. Nevertheless, many people say that a depressed person should not just be given psychotropes, but be helped in changing the mental outlook on his or her life – for example by talking to a psychotherapist. A few critics go even further. They state that the trend of taking an anti-depressant as soon as we feel sombre for some time, will mean that we loose our ability to give sense to painful events in our life. For example: if a loved-one has died, it is proper to mourn. We should not restate this as a ‘depression’ and prescribe pills in order to wipe out the mourning.

Note that it is not at all sure that practices in which anti-depressants are prescribed very easily are actually taking place in our societies right now. It is something which *might* happen, or be happening.

Glossary:

A **neurotransmitter** is a chemical substance released by brain-cells in order to 'communicate' with each other. There are many different types of neurotransmitters, for example dopamine and serotonin.

The word **medicalisation** refers to the process by which aspects of our daily life are seen in medical terms. One might for example state that our experience of food is 'medicalised' ('what does this dinner mean for my cholesterol-intake?'). Behaviour is often medicalised as well ('she doesn't sleep well, perhaps she is depressed'). The result often is, that other aspects of the same phenomenon (the joy of food, the social environment of the sleepless person) receive less attention.

[Keyword: Early diagnosis, the ‘non-ill’ patient, Alzheimer]

2. Medicine has piped me at the post

the story

Here I am with a diagnosis that I am not sure I really want to know …
A few small memory problems led me to consult my family doctor. A questionnaire, some neuropsychological tests, and different kinds of scanners followed, before I realised where I was headed. And then the big blow: possible, even probable Alzheimer’s disease. In fact, in their jargon, doctors say “Mild Cognitive Impairment”, which describes a category of people about whom one does not yet know with certainty how they will develop, but half of whom will be dangling on the irreversible side of dementia at the end of five years.

A comforting prospect! You can imagine the abyss that is opening under my feet …

And yet I feel perfectly well! Apart from this slight forgetfulness that does not really bother me, I feel normal. I should say “I still feel normal.” How terrible!

If my forgetfulness persists, I will have to take some medicine. The doctor explained to me that it will not stop the disease, but that it is often successful in slowing the most severe symptoms. And what will happen afterwards ? I do not know …

So what do I do now? Should I talk about it with my wife already? With my children? And … with my boss? I would normally have to work another five years before retiring, but won’t he fire me if he learns this? And yet I feel perfectly capable of doing my job correctly! And then there are other more down-to-earth questions: can I continue to drive my car? Can I take out additional health insurance? How much will it cost me if I tell the truth about my diagnosis?

Sometimes I even ask myself if it was really necessary to know about it so soon. So now my life is ruined. It is true that the medicine will probably allow me to put the disease off for a while. But for how much time? And I am going to spend this time watching out for the first signs of dementia, asking myself every time I make a mistake if I am beginning to lose my footing and feeling watched by those around me who will also be asking themselves if…
When will I topple over the edge? What will happen then? Who is going to decide for me? Who is going to support me, to care for me? Sometimes I wonder if it’s not better to stop it all at once….
Couldn’t they have left me alone for a few more years? Or was it better to be well informed so that I can organise my own life?

the facts

Alzheimer's disease is associated with age and thus becomes increasingly common as the life expectancy of the population increases; this represents a growing financial burden for the years to come. But the costs of this disease will also increase from the other end: by diagnosing it sooner. It is already possible to detect some very early signs of the disease using ultra-modern techniques of functional brain imaging and sophisticated psychological tests. The genetic aspects of the diagnostic have also been studied very thoroughly. Strictly speaking, the direct familial inheritance is very rare, but in the near future it will probably be possible to determine from everyone's genes a percentage of risk of developing the disease.

The pharmaceutical industry has developed medications that are currently able to slow down the evolution of the symptoms for several months to a year in 70% of the individuals on whom they have been tested. These medicines are very expensive now, but one can hope that their price will come down in a few years. Some countries reimburse their cost on the basis of often very strict conditions.

the issues

We are thus in the process of looking for a new balance between the costs and benefits of early diagnosis. It is certainly beneficial to discover a disease sooner if a treatment exists. In the case of Alzheimer's disease, a treatment is possible but not yet definitive or complete. When should it start? And for how long should it be continued? What will happen to individuals with a high genetic risk? Should they be treated from childhood? Who will pay for it? Will this influence their access to social security? Or employment? All this without even mentioning the psychological burden of these early diagnoses. How is one supposed to live with such knowledge ?

In general terms, one can ask oneself if it will still be possible to consider oneself 'in good health' since we are all carriers of a certain probability of becoming ill one day, be it dementia, cardiovascular disease, rheumatism or any other disorder. Of course, this will eventually allow us to take some preventive treatment or adapt our lifestyles in a particular way to avoid or retard the disease that threatens us. But how will society perceive all these 'predestined' individuals whose futures will be outlined in this way? How will society ensure that personal information about an individual's risk of disease is not used to their detriment?.

One of the main risks would be the destruction of solidarity and the fragmentation of social security : those who are healthy could be unwilling to pay for people who have a significant risk of becoming ill. One could also imagine that society imposes compulsory preventive measures on them, which can be perceived as a restriction of individual liberties.

All of us will probably have to learn to live with our personal risk statistics. This will be a new parameter in our way of imagining the future. Does this mean that we'll have to revise the very definition of what it means to "be ill"?

Degenerating neurons

Alzheimer's disease is a "neurodegenerative disease" which means that it is caused by the degeneration and death of nerve cells in the brain. Other well known neurodegenerative diseases are Parkinson's disease, Huntington's disease, or amyotrophic lateral sclerosis. For most of those diseases, the risk is growing with age, which means that they are becoming more and more common in our societies as the mean life expectancy increases.

Generally speaking, there are no real cures for these diseases, though it is sometimes possible to slow down the evolution of their symptoms. Much research is done, though, and there can reasonably be some hope that some solution will be found in the coming years. For example, in the disease of Parkinson, the Deep Brain Stimulation technique allows to recover some of the deficits by implanting electrodes in the damaged area of the brain (see the chapter "An electrode in the brain"). Another interesting track is the graft of stem cells, which could grow in the brain and replace the degenerated neurones. Stem cells can be extracted from adult tissues and organs, or from umbilical cord at birth, but those who seem to be the most efficient, in the actual state of research, are stem cells from embryos.

Up to now, the causes of these degenerative diseases have not been clearly elucidated, which means that there is no specific way of preventing their occurrence. But some indirect way could be through the research on "neuroprotective" drugs that try to counter the process of degeneration itself, regardless of what has generated it.

Glossary

Neuropsychological tests are specifically designed tasks to assess particular functions of the brain. For example: specific memory tests allow to determine which of the different types of memory -short term memory, autobiographic memory, procedural memory;etc - are impaired..

Functional brain imaging refers to all the techniques – mainly functional magnetic resonance imaging (fMRI) and positron emission tomography (PET) - used to visualise what's going on inside the brain without opening the skull.

Dementia is a progressive loss of the intellectual functions like reasoning and memory

Stem cells have two remarkable characteristics that distinguish them from other types of cells in our body: first, they are unspecialized cells that renew themselves for long periods through cell division, second, under certain growth conditions, they can become cells with specialised functions and can thus, for example, replace the the nerve cells affected in Parkinson disease.

[Keyword: brain enhancement, social injustice]

3. A better me

the story

> *Happy! I am incredibly happy! I passed my exams. Not simply passed. I got a first distinction! Now I am certain to obtain the scholarship for next year. The other candidates are miles behind me.*
> *And yet … something is bothering me. I had a very difficult time during the exam period. I had problems concentrating and was often tired, very tired. I resorted to taking pills. The medication allowed me to continue to studying, sometimes the entire night. I was able to absorb the material better than I ever could before. No one noticed a thing, neither the professors nor my friends.*
> *I feel a bit like a top athlete who has taken performance-enhancing drugs. I am standing on the winners' podium, but in the back of mind, I am haunted by the thought: 'I hope no one finds out that I have cheated.'*

the facts

While it is perhaps not the intent to develop medication to improve ourselves, it is likely that drugs created to treat illness will also be able to enhance our natural abilities. Medication to treat Alzheimer's disease is likely to considerably improve normal memory functioning as well. Stimulating medicines, now used to treat children with attention deficit, also increase the ability of the 'normal' brain to concentrate. One's emotional state can also be improved. The new generation of pharmaceutical drugs to treat depression also have an effect on people who do not suffer from depression: people who take them are less concerned with small everyday worries and live life more optimistically and with more confidence. In stead of being used for therapy, these drugs might one day be employed for enhancing the normal body, brain and psyche.

the issues

With all these envisioned benefits of taking these drugs and 'enhancing' ourselves, will it be inevitable that they will be taken for this purpose? Can we or even should we try to limit this?

You can, of course, ask yourself what is wrong with expanding our brain capacities using pharmaceutical drugs. Wouldn't it be wonderful to find a way to make ourselves more intelligent, to make our brain perform better? You no longer need a shopping list. You could read a text once and it would be engraved clearly in your memory. You could throw away the calculator because you would be able to perform the most difficult calculations in your head. Students would no longer need to cram for exams…

The question is certainly valid if it appears that these drugs are not harmful. What is wrong with increasing memory, intelligence, level of attention, the ability to concentrate? Or even enhance our creativity, empathy, or sociability? We already take refuge daily in coffee, coke (Coca Cola or other branches) , a cigarette or an aperitif before dinner. Don't we do this mainly for the effect of the caffeine, the sugar, the nicotine and the alcohol on the brain? Or is a pill different than a cup of coffee?

Besides, there might be situations where it is quite well possible that medicines which improve normal functions could be very useful. Military scientists look for medicines that could keep soldiers or pilots on a mission alert for longer periods of time. According to the military an improvement in normal brain functioning could mean the difference between life and death. Or what about the older employee who is sometimes slightly forgetful? Would anyone deny this person access to memory enhancing medication if he or she could stay on the job for several more years?

On the other hand, would the wholesale use of 'intellectually stimulating medicines' not thoroughly change society? One could ask whether the values that we adhere to today might fall out of fashion in favour of performance and immediate pleasure without effort. Wouldn't we all become like athletes who take stimulants, EPO or steroids to boost their athletic performance.

Moreover, the question is whether we as individuals even have a choice in the matter. If all of your children's friends perform better at school due to pharmaceutical drugs, it will be difficult to choose a 'natural' school career. Or, if your chances of professional promotion always fail because of your pill-swallowing colleagues …. In short, if 'everyone' takes refuge in these drugs, perhaps we will need to follow the general trend in order to keep up.

Additionally, who will pay for this type of enhancement? Will it be society through the public health system, each person out of his or her own pocket or through private medical insurance? In the two last cases, especially the wealthy will have the luxury of increasing their brain capacity and that of their children. This means that they will more easily gain access to the best schools, the most prestigious universities and the best jobs. This would reinforce existing social inequality.

Beyond biological limitations

In pursuing superior performance, humans have always sought advantages obtainable from better training and practice (education), better tools and equipment (technology), better knowledge (science), better nutrition and health (medicine), ….

In the recent past, and even more so in the future, we may find help in new technological capabilities for directly improving our bodies and minds, not only by drugs, but also by genetic modification, surgical procedures and the implantation of all kind of devices, from plastic hips to fancy electronics.

Some people believe that humanity will be radically changed by technology in the future. They foresee the feasibility of redesigning the human condition, including such parameters as the inevitability of suffering and aging, and the limitations on human and artificial intellects and psychology. They wish to use technology to extend their mental and physical (including reproductive) capacities and to improve their control over their own lives beyond current biological limitations. The resulting 'trans-humans' will be superior creatures compared to the human beings we are today. According to the people who support this view it is a wonderful thing that we have the chance to control and to direct our own evolution.

Glossary

Therapy versus enhancement: Therapy is the general term for the treatment of individuals with known diseases, disabilities or impairments. Therapy tries to restore them to a normal state of health. The term enhancement refers to the alteration of the 'normal' state of the body, mind or psyche with the aim to improve the performance and the 'natural' capacities.

[Keyword: electrodes in the brain, brain surgery]

4. An electrode in the brain

the story

> *I have Gilles de la Tourette syndrome. I am severely affected: I have compulsive thoughts, must loudly clear my throat, shake my head, and sometimes I hit my belly so hard that I have to take stomach tablets afterwards. The constant tics of my head have worn out two vertebrae in my neck. I am unable to control this.*
>
> *Of course, I have searched high and low for help. I have tried everything: medicines, therapies, I was even admitted to hospital for five months to try out all sorts of tablets. Nothing helped. Then I heard that there was a neurosurgeon who had tried something new with Tourette patients that entailed attaching wires and electrodes to the brain. I saw a videotape of a similar operation on a patient with Parkinson's disease. It was a scary sight, but I still wanted to speak with the neurosurgeon.*
>
> *She explained everything to me. It came down to the operation allowing me to adjust the strength of my symptoms by increasing or decreasing the current. However, there were also risks attached. They must drill into your head, meaning the possibility of bleeding or an infection. In any case, it would be a major operation with many checkups afterwards.*
>
> *I hesitated for a long time, until I saw a video of myself at a party. Then I thought: I can't go on like this. I requested the surgery. After many preliminary examinations and discussions, I was operated on. The electrodes were inserted into my brain, approximately seven centimetres deep. Wires were placed under my skin, to my collarbone, where they are connected to a sort of pacemaker located there. I am able to increase or decrease the current via a remote control aimed at this device. The more current, the less trouble I have due to my symptoms.*
>
> *It is not ideal. I literally feel the current surge through my head; it feels like a sort of bang or pop, very uncomfortable. It also makes me dizzy. In addition, the wires stick to my connective tissue, and I experience a pulling sensation. The symptoms are still present, but the current keeps them under control. I set the level of current high when I go to work or am among people. At home or when doing sports, I set the current lower to eliminate the dizziness.*
>
> *The operation is nothing to be sneezed at. Yet, overall, I am happy with it. I had major problems: physical problems of course, but socially things were also becoming problematic. Nothing else helped, and now can I live a fairly normal life.*

the facts

The story above is not science fiction, but is based on the account of a Dutch man with Gilles de la Tourette syndrome. The technique in which electrodes are placed directly in the brain is called *Deep Brain Stimulation* (DBS). It was developed in the eighties for patients with Parkinson's disease. In the meantime, Deep Brain Stimulation has become a rare but accepted treatment for patients with Parkinson's disease when medicines do not or no longer work; two thirds of the patients claim to have benefited from it. The operation is still in the experimental stage for Tourette patients; less than ten patients in all of Europe have been treated in this way.

Operations on the brain are not looked upon favourably by the public, and understandably so. Between the nineteen-thirties and nineteen-fifties, hundreds of thousands of psychiatric, mainly schizophrenic patients received a prefrontal lobotomy. This meant that the nerve bundles in the prefrontal lobes of their brains were haphazardly cut. These patients did not improve much and often became apathetic. However, they became more manageable for those around them. Lobotomies are outdated now. In retrospect many find it shocking that patients were changed into ‘vegetables’ because those around them did not know how to handle them.

Deep Brain Stimulation differs in a number of major respects from this type of practice. The operation is quite precise and does not destroy healthy brain-tissue. It is also reversible; in principle, the electrodes can be removed from the brain of the patient. Most important perhaps is the fact that the patient himself is able to decide whether he wants a surge of current – a considerable difference with respect to earlier psychiatric patients.

the issues

At the present time, DBS is primarily an operation intended for people with a movement disorder such as Parkinson’s or Tourette syndrome. However, experiments are in progress with psychiatric disorders such as OCD (Obsessive Compulsive Disorder). Thus, treatment of psychiatric patients for whom other treatments have failed via DBS is slowly becoming a reality.

The question remains whether DBS will ever become a routine operation. The treatment is expensive and is hard on the patient. In the case of psychiatric disorders, doctors as yet do not know precisely enough where in the brain the electrodes should be inserted to treat the disease.

Many also question whether the operation *should* become routine. In the case of an illness like Parkinson's disease, DBS is perhaps not so alarming. After all, in this case the operation *restores* control of the muscles that the patient has lost. However, would we want to treat psychiatric disorders through the implantation of electrodes? Then we are perhaps on the road to mechanically *changing* people. Many believe that, in these cases, it would be better if our attention was focused on the behaviour and self-image of the patient, his or her social surroundings, and the quality of the psychiatric care provided. Perhaps much could be improved in this area. The question is the following: do we want to view psychiatric disorders as electrical problems? What is the benefit of this? And what do we lose in the process?

Cyborg

Due to the presence of electrodes in his head, the Tourette patient in the story above is, strictly speaking, a *cyborg*. The term cyborg is derived from *cyber*netic *org*anism, which means: organic robots, or human machines. Cyborgs are people who have been fused with technology.

This sounds futuristic, but most of us are also cyborgs. Think of cardiac valves, pacemakers and artificial knees, but also of fillings, contraceptive injections, contact lenses or silicone breasts. All of these are artificial 'improvements' of our natural body.

The question is whether we wish to continue to travel this path of ever-increasing levels of artificiality within our body. Some people believe we should not; they fear becoming too far removed from our nature and thus ceasing to be 'persons'. They would, for example, have the following to say about the Tourette patient cited above: is the patient controlling the electrodes, or are the electrodes controlling him? Who is the boss, the person or technology? Many science fiction films play with the fear that technology will take over our body in the future.

Cochlear implants

Deaf people sometimes have an electrode placed in their ear that allows them to hear again. This electrode translates sound waves into nerve impulses. The difference with 'normal' hearing aids is that the electrode is located *in* the head. People with such an implant also need a sort of microphone to transmit the sound waves to the electrode.

The technology is not yet perfect. In addition, not all types of deafness can be corrected with this technology. This is not a case of Deep Brain Stimulation, since the brain is not operated upon. Strictly speaking though, this cochlear implant transforms people into cyborgs.

It is a striking fact that not all deaf people eagerly welcome these implants. Some feel discriminated against by this; why do a majority of the deaf minority think that their 'deafness' is

an ailment that must be treated? This changes us from people into patients, say the deaf. The deaf community is also afraid that their sign language will die out because of this type of technology. They argue for the preservation of their language and culture, just as endangered ethnic groups do. The fact that the technology is as yet imperfect complicates the issue. Deaf people with a cochlear implant are at the moment neither deaf nor hearing, as it were.
A tricky point here is the fear of the deaf that their children who are born deaf will become estranged from them because of this technique. After all, if these children acquire an implant soon enough, they will be able to function in the same ways as naturally hearing people and learn to speak. May deaf parents then refuse to have such an implant performed on their child?

Glossary:

Tourette syndrome is a neurological disorder, characterised by involuntary movements and uncontrollable vocal sounds called tics.

Deep Brain Stimulation is a relatively new technique by which a neurosurgeon implantates one or more electrodes directly into the brain of a patient. As a result, the patient behaves differently.

[Keyword : Brain and behaviour, neuro-imaging, genetics, free-will, responsibility, neuro-marketing, mind and brain]

5. Reading in one's brain

the story

> *This young delinquent leaves me rather perplexed. In fact, I seem to be faced with this new kind of dilemma more and more in my career as judge. Responsible or not?*
>
> *Let me explain. This young man is violent. He has always been this way. And, in his family, this even seems to be a characteristic that repeats itself from generation to generation. That is the real problem here and in fact his lawyer claims that he is not responsible for his violence as it is a predisposition he inherited from his parents. And that, by the nature of things, he was also educated in an atmosphere of violence. And that, cause or consequence, his brain has not developed the mechanisms that would allow him to suppress his violent drives. It seems that one can even visualise this on a scan. "His prefrontal lobe contains 10% less grey matter than usual," the neuroradiologist's report notes. For this reason, his lawyer calls for acquittal.*
>
> *OK. But with this type of argument, are we not running the risk of coming to the point at which no one can be considered responsible for his or her actions anymore? Worse. Someone might tell me some day that certain crimes could not be avoided because its author could not act differently given what his brain was telling him to do.*
>
> *I am ready to grant this young boy all sorts of attenuating circumstances, but don't we have a right to expect him to be able to master what his brain makes him do or not do? After all, he is a human being, and we expect from him what we expect from any human being. If we don't, it could mean that we consider him as not being worthy of being human! Unless, of course, we consider him mentally ill, immature or demented, in which case he should be cared for and/or protected. But this is not the case, the experts say.*
>
> *I do have to judge his acts and not the scans or genetic analyses. And the act which he has committed is serious and socially unacceptable. What should I do?*

the facts

Progress in medical imaging technologies allows scientists to visualise not only the anatomy but also the functioning of the brain in detail. This makes it possible to look for links between areas of the brain and particular actions or emotions. For example, scientists have shown that reading a word and speaking it do not activate the same areas of the brain. Being sad or being afraid do not do so either.

Other research seeks to establish links between particular characteristics of the brain and certain behavioural trends such as homosexuality or attraction to extreme sensations. A very controversial American study has thus demonstrated that people with impulsive and aggressive tendencies have less developed pre-frontal lobes (behind the forehead) than the average. This is an observation that can be calculated only by comparing statistically average values measured in a large number of people, but it does not make it possible to make a diagnosis about a particular individual.

the issues

And yet some people have already used such arguments to get a particular adolescent murderer acquitted in the United States. This raises questions that go beyond the simple fact of administering justice. In fact, if one thinks that our brains “decide in our place”, does this not essentially mean that we no longer have either liberty or free will? Would it not reduce our brains to no more than computers that execute actions on the basis of predetermined programmes or according to parameters dictated externally, of the kind “such input leads to such a response”? Some philosophers do in fact go that far. But most think instead that, even if our brains are the place where thought occurs and actions are determined, it is the person as such who thinks and takes decisions. The question then becomes whether there is a difference between a person and his or her brain. And what makes this difference?

Some people also imagine that one day it will be possible to predict a person’s behavioural tendencies on the basis of images of his or her brain, by comparing them with “tables” of averages as we do for the weight and height of babies. In the perspective of a very rational society, one would thus be able to test children to detect a possible gift for music, mathematics or competition, in order to better orient their education … It could also be possible to check whether a future employee has tendencies to depression, racism or antisocial behaviour … Or even to set preventive tests to detect possible aggressive or paedophile tendencies for all citizens in order to impose “normalising” treatments – or preventive imprisonment - even before their inclinations reveal themselves. Of course, this is science fiction…

Nevertheless, some “neurotechnolgy” companies are actually developing highly sophisticated equipment based on the latest discoveries in the neurosciences, which involve commerce and security more than medicine. A good example is the “brain fingerprinting”. This is a kind of super lie detector that makes it possible to use brain waves measurements to confirm whether an individual does or does not recognise aspects of a crime that are presented to him on a screen. For example, a photo of the scene of a crime is presented to a murderer who claims not to know this place. But the equipment detects that the image does indeed awaken a memory in his or her brain … This equipment is used by investigators and judges in the United States, but its producers are also promoting it among employers or in the security services. In airports, for example, one could test everyone arriving from a particular country for the effect of images involving terrorist training. Another example is what's called neuromarketing : based on the analysis of brain waves, marketers can now determine which scenes of a TV-advertisement (or of an electoral spot) are the most efficient to influence the consumer …

In fact, this probably reminds us of a nightmare we all had once: that somebody was able to read our thoughts! Will we ever get that far? Probably not. But all those scraps of intimacy that the brain technology equipment is able to decipher today are putting in question the very definition of privacy and of freedom of thought.

The technology of brain reading

There are two main ways of looking into our brain without opening the skull:

- Scanners are used to look at the structure (anatomy) of the brain. They 'see' through the bony skull and create contrasts in the rather uniform grey mass of our brain. Some of them give very fine pictures, which usually require a long time to take them. They are especially useful for detecting anatomic abnormalities like tumours or strokes. Other sorts of scanners give a rather blunt but very rapid image; they can give immediate information about the modifications occurring in the brain during different circumstances, for example while performing a sum or thinking about someone we love. The images can be used to study the functioning of the brain.
- The other way is to measure the electrical activity of the brain (brain waves) to get an idea of its functioning. Computerised treatment of these data can provide maps of the brain's activity.

By combining the data obtained through different methods, the scientists can nowadays really see on their computer screens what is happening in our brain.

Glossary

Free will and **responsibility** are philosophical concepts, which relate to our deep-held beliefs that we, humans, can determine our behaviour, rather than let it be determined by external events, and thus that we are responsible for our actions..

[keywords: brain plasticity, cognitive neuroscience, importance of environment]

6. Young minds. The making of …

the case

> *Barbara pokes her tongue out, she pulls faces, laughs out loud, looks to the left, to the right, pokes her tongue out again. On her lap is a newborn baby. Only four hours old. The baby is looking at her. Eyes wide open. Barbara pulls an angry face at him … and the newborn reacts. He imitates the face of Barbara. His eyes try to follow the eyes of Barbara … up, left and right. He maps what he sees in the face of Barbara onto his own face. And yet he is only a few hours old, even far too young to recognize himself in the mirror.*
>
> *Barbara is a cognitive neuroscientist. She is interested in how the human brain works, how it develops and how it learns. She works with very young children, from newborns to toddlers. Although newborns can't speak, aren't all that eager to follow instructions, can't fill out questionnaires, push buttons or play with cubes … Barbara is able to communicate with them. She knows that newborns are shaped by evolution to have very important face-to-face contacts with other human beings.*
>
> *When Barbara looks at the newborns, she does not see, as most of us do, a picture of innocence and helplessness, a 'blank slate'. Barbara sees human beings who have expectations, who are very sensitive to their social environment and who have ideas about the world, about objects, about other human beings. Already at birth, babies seem able to distinguish human faces and voices from other sounds and sights. These inborn initial ideas seem in any case more complex than just reflexes or responses to sensations.*
>
> *Within days, the baby on Barbara's lap will recognise familiar faces, smells, sounds and voices. He will be able to express his preference for the familiar signals compared to the unfamiliar ones. Apparently the inborn initial ideas are further shaped, revised and reworked by the experiences the baby, the infant, the child goes through from the very beginning of live. Therefore, when Barbara looks hat the newborn what she also sees, is a powerful learning machine ... perhaps the most powerful learning machine in the universe.*

the facts

For centuries, we have viewed infants as creatures who passively absorb bits and pieces of information from the environment. Today, the situation is very different. Scientists have probably learned more in the last thirty years about the brains and minds of very young children, than in all recorded history.

Scientists like Barbara know that babies construct their brains at a phenomenal rate during the first years of life. They not only shape their brains but also begin to form their feelings, thoughts, character, imagination, intelligence, awareness of others and openness to the world. It is during the first years in life that the 'wiring' of the brain is establishing itself most intensively. The billions of brain cells sprout and reach out to their neighbouring neurons to establish contact. Every time the infant experiences or feels something, its brain creates these new connections, somewhat as if they were linking their ideas together. The development of these communication lines between neurons causes a spectacular increase in the size of the brain. But, according to some scientists, in order to develop harmoniously and sociably, the brain of the baby not only needs proper stimulation, but, above all, … warmth and love.

the issues

In today's hectic society, it is not always easy for parents to provide ideal conditions for their baby to develop its brain. Parents are often compelled to return to work soon after the baby is born, be it for financial reasons or for the needs of a career-plan, and this confronts them with some critical dilemmas.

Take for example breast-feeding. Some scientific studies have discovered that breast-feeding is not only important on the nutritional point of view, but that it may actually boost the development of the brain of the baby. How this happens remains unclear, perhaps through the development of mutual bonding-attachment between mother and child, which, as said before, is essential for the normal growth, development and functioning of the brain.

In some Western countries, though, breast-feeding is sometimes considered as old-fashioned and counter-productive, and it has become less popular. Some mothers, who want to breast-feed, complain that they do not get enough information and support from their medical caregivers. Others are not able to continue breast-feeding past their maternity leave because of practical problems to combine it with work. Therefore, organisations like the World Health Organisation and UNICEF are calling for extended maternity leave and paid breast-feeding breaks to be added to an international maternity treaty. On the other hand, some people are afraid that putting more emphasis on mothers' rights would reinforce the current the unfavourable treatment of females by employers.

Of course, proper stimulation of infants and children goes far beyond breast-feeding, and does extend to loving fathers or male role-models as well! It is now clearly established, according to some scientists, that an inadequate social surrounding with lack of empathy has a negative effect on the cognitive, emotional and social development of the young child. Sometimes parents do not have the ability to provide the best environment for their baby's development, either due to financial reasons or lack of awareness of ways to stimulate their children, particularly if their own childhood lacked stimulation. However lack of adequate stimulation can be encountered in all social classes.

Parents short on time, but not on budget may show their affection, by buying expensive toys, computers, stereo- and television sets. Some scientists warn that this form of 'object-mediated love' might be one of the most dangerous constraining factors for empathy development. It represents a potential serious negative conditioning factor of future generations.

However, on the importance of the first three years of life, there is far from consensus between the scientists themselves. Although most scientists agree that the first months and years are important in the development of the human brain, some accentuate that this period should certainly not be considered as all-determinant for later life. According to them, some of their colleague-scientists overemphasize certain findings over other well-respected theories and results in the fields of cognitive neuroscience and developmental psychology.

These fields in neuroscience remain complex and it happens that complete opposite research results are published. Indeed, some studies have shown that children who are admitted too early in crèches have a significantly higher risk to manifest behavioural problems later on in life. An explanation might be that the two first years of life, - typically the years in the day-care centre - are the period where the child develops its sense of empathy and the regulation of its emotions. If the face to face interactions are not of a sufficient quality during this period, it can interfere with the development of the child's personality and social skills. However other studies have actually shown better outcomes on some measures (social skills, language) for children who have day-care in group situations outside the home. It should be taken into account though that many studies on issues of childcare make clear that it is extremely difficult to separate out various factors, such as income, education, skill of parents, access to non-parental caregivers, health care. Besides, the differences that are sometimes found between groups are quite small. But above all, the relation between research findings in a highly controlled setting and the 'real world' is not simple and unidirectional. Thus research results should be interpreted with caution. Nevertheless, it remains clear that new insights in the development of the brain of children and youngsters will bring on edge the discussion on the way we raise our children, but also on the education and social system as a whole.

The brain, a plastic organ

Brains never cease to evolve. Up to some twenty years ago, scientists thought that the brain did not change further once the learning period of infancy had ended – except in the sense that nerve cells were lost in the aging process. But we now know that brains preserve a remarkable ability to adapt and remodel themselves at all ages.

It is also the plasticity of the brain that makes it possible to revive certain functions even after for example a stroke. Although certain brain areas can be completely destroyed by the stroke, other areas might assume the connections and regain functionality.

Words … sharp as scalpels

Brain plasticity is a relatively new concept. It assumes that the brain is a continuously plastic organ and that we basically learn all the time. This learning results in our brain constantly being modified by all our experiences. This new theory opens new concerns, especially about the media. Words, images or events can act as sharp as scalpels, or as potent as drugs, in the sense that they can actually change our neuronal circuits. The mass-media thus play a crucial role through day to day exposition, and there is great potential for (mis)use of its power. Some philosophers even believe that the media environment created by ourselves is much more dangerous than potential future manipulation of the brain by pharmacological or genetic means.

Glossary

Cognitive neuroscience is the field of study, which tries to understand how mental processes take place in the brain.

Developmental psychology is the field of study, that investigates the way how cognitive processes change throughout lifespan.

Neuroplasticity is the lifelong ability of the brain to form and reorganize connections and networks between neurons. When we learn or memorize, there must be persistent functional changes in the brain that represent the new knowledge.

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(*Text for back cover*)

Brain science is a hot topic! Scientists are moving ever closer to being able to connect what we experience to certain parts of the brain. For the first time ever, we might actually be able to see what makes us feel, think and act the way we do.

These developments raise a number of questions that are very important to everyone. The prospect of artificially repairing a damaged brain gives hope to many people suffering from brain afflictions. But the availability of increasingly sophisticated ways of manipulating the brain gives rise to concerns: Who exactly will make these changes? Why will they make them? And will this process bring about a fundamental change in us as human beings?

This brochure focuses on six aspects of brain science. We meet a mother whose son has ADHD, a student who took pills to improve his exam results and a man who knows that he will develop Alzheimer's disease at some point in the future, but doesn’t know what to do about it. Each topic starts with a realistic example, followed by a short presentation of the facts and an exploration of the societal issues and concerns raised.

Written in language accessible to the layman, this brochure is meant to serve as a starting point for discussions on the impact of brain science.