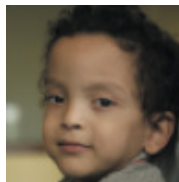


May 2010 N° 8

COGNITIVE DIFFICULTIES

Infomotrice

UNDERSTAND AND DO SOMETHING ABOUT THE INVISIBLE HANDICAP !



Dear friends,

When I read in this letter Sébastien's story, I recall his cries for help and those of François, Matthieu, Guillaume, Clémence, Alexandre or Aurélie, faced with tremendous difficulties that nobody around them could understand : to calculate, to recognize images, to orientate themselves or not to be overwhelmed by their emotions...

Everybody could see the wheelchair and the clutches and understand that school should be made accessible. But it was different for these other difficulties. The teacher was saying: « He is not interested, he does not pay attention. » The orientation advisor was saying: « He will not be able to progress. » Furthermore, each child was different and what one could do easily was a nightmare for another.

Slowly, however, the understanding of these difficulties improved. Thanks to people like Clair Meljac, Françoise de Barbot or Michèle Mazeau, we started to put words on these cognitive difficulties, to evaluate them, to invent « remedies » and signals, to guide these children, to inform teachers and administrators, to train professionals to give the children a chance to succeed.

Among very premature babies, one out of two will suffer from motor or cognitive difficulties. That is why, when you read the interview by Sybille Gonzalez, you will see why it is essential for La Fondation Motrice to support her research with children. You will know that, thanks to you, we are able to give her the means to understand those difficulties and invent answers.

It is because you give us the means to create teams within La Fondation that we have been able to attract interest for a partner such as Sodiaal and launch a vast research project on the cognitive development of the children and identification of practical solutions in collaboration with French and European teams.

When in a few years time you see a young adult able to orientate himself despite his CP, this child that a teacher has supported till the end of his learning project or helped find a job, you will know that it is in part thanks to you that this progress was possible.

Thank you,

Dr. Alain Chatelin, Chairman of the Board

Cerebral palsy affects 1 out of every 450 children born.
There are 125 000 children and adults suffering from CP in France.
Premature birth is one of the main causes.
Any family can be affected!

Your generosity is our only revenue source to promote
research on cerebral palsy, care and support for patients.
THANK YOU FOR YOUR DONATIONS

COGNITIVE DIFFICULTIES: THE INVISIBLE HANDICAP

LITTLE KNOWN AND INVISIBLE COGNITIVE DIFFICULTIES ARE HOWEVER VERY MUCH ASSOCIATED TO CP AND INCREASE THE PERSON'S HANDICAP

➔ **Read a map, classify papers, bring a glass to the mouth, write with a ball pen are all simple movements that a person suffering from cognitive difficulties will find hard to do on her own ...**

What are cognitive difficulties?

Cognitive difficulties affect cognitive function through which we are able, *inter alia*, to interpret information, to acquire and organize knowledge, to plan and control our actions and exchange with other people.

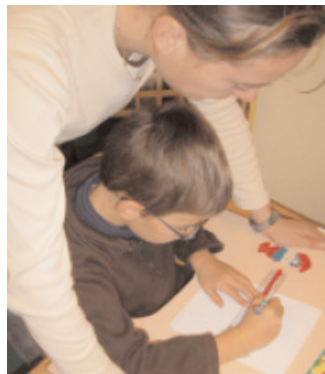
For a very large number of persons with CP, motor function problems are associated with cognitive difficulties.

The difficulties appear when the child has problems learning at school or for certain movements of daily life, even when the reasoning and intellectual capacities are not affected.

This learning handicap and the difficulties it creates are specific, resulting from different combinations of problems.

The most common cognitive difficulties affect, for instance:

- concentration and attention,
- certain aspects of memory,
- writing and reading,
- spatial or body perception, which affect movement execution,
- capacity to recognize images or signs involved in reading or writing.



One person may have the capacity to conduct a highly complex mathematical reasoning and be unable to keep his/her accounts because of “discalculation”.

Another difficulty is dyspraxia that hampers planning and automatic execution of certain moves: the person topples a glass, drawings are mediocre, attention is only focused on voluntarily controlling a move that is not automatic.

Even if motor and cognitive problems are in theory independent, they in fact combine and increase their mutual impact. For instance, a person who walks with difficulty will have little activity and therefore will not be able to develop or improve her sense of spatial orientation.

Similarly, disturbances to executive functions, essential to execute and control movements, will worsen other motor problems such as spasticity (or hypertonicity).

Finally, cognitive problems like motor problems are influenced by emotional factors: a stressful situation, for instance, will increase difficulties.

The importance of diagnosis and care

Cognitive difficulties are often wrongly diagnosed and current statistics are therefore probably under-evaluated.

Because they are not well known, it is difficult to understand the problem that CP patients face. For instance, attention deficit might be attributed to a lack of “motivation” before the real cause, i.e. cognitive difficulties, is diagnosed.

Learning difficulties at school could therefore be treated more efficiently if communication between family, teachers and carers were better organized around these problems.

Early diagnosis and care represent a strong challenge, which is to give access to school, to a job and wider autonomy in their daily life to people suffering from cognitive troubles.

A priority for La Fondation Motrice

Thanks to a partnership with SODIAAL, the largest milk coop in France, La Fondation Motrice has established a group of experts to identify the research priorities in this area. Their work will lead, *inter alia*, to a seminar on cognitive difficulties and to a call for specific projects.

The logo for SODIAAL, featuring the word "SODIAAL" in a stylized, blue, serif font, enclosed within a thin black rectangular border.



COGNITIVE DIFFICULTIES MUST BE DIAGNOSED EARLIER: A CHALLENGE FOR CP RESEARCH

➔ **Dr. Sibylle Gonzalez-Monge, a neurologists, works with the Pediatric Rehabilitation Department of Escale, a hospital in Lyon. With her team, she tries to develop means to evaluate visual perception disturbances in children. La Fondation Motrice provided financial support for 2 years to prepare the study.**

What kind of research has been conducted in your department?

It is a two stage study.

The first stage took place in 2006 and 2007 and was conducted by a doctorate student, Virginie André, who developed a procedure to evaluate basic visual perception, i.e the brain capacity to process the visual information it receives. These two years of research benefited for financial support from La Fondation Motrice.

The second stage, led by our department on the basis of this preliminary work, aimed to statistically validate the results obtained during the first stage, to establish reference data that will soon be made available to professionals to help them in the evaluation of visual perception disturbances in children.

We are now preparing to publish the report that will conclude our research.

Can you describe this evaluation procedure?

We built our test on the basis of a series of neuropsychological tests for adults.

It includes 6 subtests, 4 to evaluate basic visual perceptions (cf. hereunder) and 2 to evaluate visual and spatial perceptions (localisation and discrimination of points).

The test was taken by 96 “ordinary” children, divided in 4 age groups, from 4 to 12 years of age.

The statistical processing of the results provides standards that permit to evaluate difficulties in this area that can be linked to one or several of these subtests or all of them.

What did you learn from the study?

The first benefit is that we now have a better understanding of the visual perception function development. Some previously held beliefs have been contradicted. It is very often said that a very young child is mostly “visual”, before developing the language, and that visual functions form therefore very early. Thanks to our study, we observe that these functions develop progressively as the child grow older, from 4 years, and that they do not mature as early as was thought.

The second thing is that it allows an early diagnosis of visual perception issues. Thanks to the first series of tests, it is possible to evaluate the processing of visual data by the brain occipital zone, and with the two tests of spatial and visual perception we can evaluate

treatment by the dorsal way (through which data are transmitted from the occipital to the parietal lobe; the dorsal way also processes the spatial localisation of visual stimulus). It is particularly important with CP, as it is very often linked with dorsal way dysfunction that cases visual and spatial dyspraxia.

Finally, the tests have been developed in such manner that they can be used for children with speech difficulties, as they do not require a verbal answer: being able to show “yes” or “no” is sufficient to answer questions. That means that children will not be penalized by their speech difficulties and will be able to benefit from a better diagnosis.

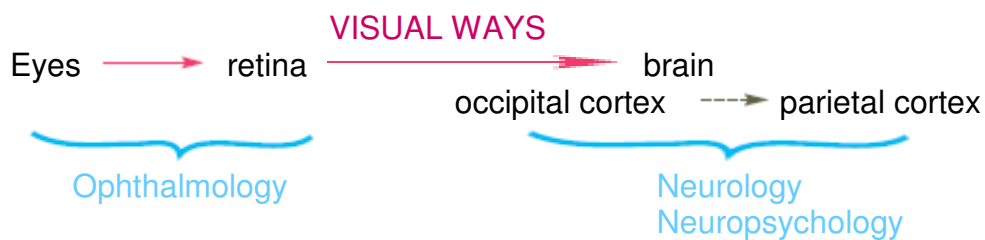
Tests of basic visual perceptions

12 items by subtest

The child is requested to answer “same” or “not the same”

- Perception of length: horizontal bars of same or different length
- Perception of size: circles of same or different size
- Perception of linear orientation: lines of same or different inclination
- Perception of middle: segment cut or not cut in half.

Visual information circuit and treating disturbances



LIFE WITH COGNITIVE TROUBLES

SEBASTIAN'S TESTIMONY



I am increasingly hampered by these difficulties.

In daily life, even though my parents help me a lot, I am increasingly hampered by cognitive difficulties, to find physical and psychological resources or to get organized.

When I was younger, these difficulties were not such a problem, except at school for geometry class or spatial orientation. But as I grow older (I am 36), as I gain more autonomy it becomes more urgent to find solutions as my cognitive difficulties combine with motor problems.

To obtain a job, practical organization troubles made it difficult for me to complete or read a double entry chart, or execute several tasks simultaneously. Today, I am an Education Department secretary in a Paris university and I am lucky that my boss and my colleagues understand my difficulties. Thanks to that good work climate, I can do more work.

It took me a long time to identify the problem and it is still difficult to make people understand it

When I reached the age of 13, I started asking myself why I had problems with algebra and geometry even if I knew that it was "normal" to have them in geography because of CP. My parents explained to the teachers that these difficulties were very specific: why another pupil whose motor problems were a lot more severe than mine had no problem with maths? There is no "template" for cognitive difficulties! They are extremely complex, as I discovered thanks to Apetreimc* and La Fondation Motrice.

It is also difficult to make people understand that concentration is not always possible ("in another world") and that movements are slow. At the end of a workday, one is tired and difficulties increase: that is when we need help for every daily act.

It was hard finding help

I had to ask to follow an eye rehabilitation programme and I found the psychostimulation medication which I take today to help my concentration on an Internet forum for parents of children with dyspraxia!

I try to be in contact as closely as possible with professionals with a detailed knowledge of these problems who are in a position to provide practical solutions. For instance, Dr. Gastal's team at Cechoia** helped me obtain a carer to help me in my daily life, even though I did not qualify for one "only" on the basis of my motor difficulties. Without their help, I would not have as much autonomy as I have today.

But I still need an ergotherapist to help me improve my professional qualification and also someone to give me advice on how to improve my daily life.

I still do not know how to manage my cognitive difficulties

I do not know how to handle my handicap, whether I should take care of my motor handicap first and my cognitive difficulties after, or both at the same time.

What should come first: concentrate or stretch my legs to avoid pains? Where should I focus my efforts: on motor stability or on the movement that mobilize my eyes and my hands?

Still a long way to go ...

I have the feeling that cognitive difficulties have been somewhat “forgotten” compared to motor problems. The gap is slowly being reduced but there is still a long way to go.

**Apetreimc: Association pour l'Education Thérapeutique et la Réadaptation des Enfants Infirmes Moteurs Cérébraux*

*** Cecoia, Hôpital national de Saint Maurice : department for CP patients.*



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Registered as a « government-approved and endorsed public foundation » in July 2006

President : Dr Alain CHATELIN – President of the Scientific Council : Pr Marie VIDAILHET

Patron : Mr Andrea CASIRAGHI

Founders : APETREIMC (2005), SESEP (2005), CDI (2005), PASSERAILE APETREIMC (2006)

La Fondation Motrice
is a partner of la FRC



SUPPORT RESEARCH ON CEREBRAL PALSY, NUMBER ONE HANDICAP IN CHILDREN

Dear Sir, Dear Madam,

Cerebral palsy affects 125 000 persons in France and 1 out of 450 children born

Cerebral palsy results from brain damage suffered during pregnancy or at birth. It has lifelong consequences, such as several forms of palsy frequently associated with cognitive, perception, sensorial, communication or behavioural difficulties.

We can do something to help these children and young adults who suffer and are ignored !

From prevention to care, at every level of the pathology, many decisive improvements are possible. But we need your generosity to succeed.

If you pay taxes, including on wealth, you can benefit from a tax allowance representing 66 to 75 % of your donation.

Thanking you in advance for your support,

Dr. Alain Chatelin
Chairman of the Board

MARIE : JE CROIS QUE J'AI DEJA TRADUIT LE BULLETIN DE SOUTIEN. SI CE N'EST PAS LE CAS, DIS-LE MOI. JE LE FERA PAR RETOUR;

WHY SUPPORT RESEARCH ON CEREBRAL PALSY?

Cerebral palsy is the most common motor handicap in children

Cerebral palsy results from brain damage suffered during pregnancy or at birth. It has lifelong consequences, such as several forms of palsy frequently associated with cognitive, perception, sensorial, communication or behavioural difficulties.

La Fondation Motrice is a state-approved research foundation.

La Fondation Motrice was created in 2006 is the only French association dedicated to cerebral palsy research.

Knowledge research and communication facilitate prevention of brain damage.

What do we do with your donations?

La Fondation Motrice is present in every field of research that are essential to help children and adults with CP to progress.

For instance:

- with € 180 000, we financed the development of a special seat for babies who undergo brain scans to evaluate brain function during speech development;
- with € 30 000, we finance one year of doctorate study on brain damage mechanisms at birth, to help develop medications.

HOW DO I SUPPORT LA FONDATION MOTRICE?

You can send your donation:

- **by check**, to La Fondation Motrice, addressed to :

LA FONDATION MOTRICE
67 RUE VERGNAUD
75013 PARIS

- **on the Internet**, on our website: www.lafondationmotrice.org

- **by bank transfer**, to La Fondation Motrice, 01 45 54 03 03.

BENEFIT FROM TAX ALLOWANCE

By donating to La Fondation Motrice you will benefit from a tax reduction of 66% of your donation, up to 20 % of your taxable income.

When you give €500, the real cost to you is €170.

You will receive by mail a tax receipt to be annexed to your tax return.

If you are subject to wealth tax (ISF) you may benefit from TEPA act : 75 % of donation amounts can be deducted from your tax, up to € 50 000.

If you donate € 2000, the real cost to you will be € 500.-

If you want to bring your wealth tax to zero, you just have to make the following calculation:

$$\text{My ISF amount} \times 1.34 = \text{amount of my donation to La Fondation Motrice}$$

Therefore, if you ISF tax amounts to € 1 500, by donating € 2000 ($1\,500 \times 1,34$) simply enclose your tax receipt with your tax return.

Your donation must be dated June 15th, 2010 at the latest, which is the deadline to declare and pay the 2010 wealth tax. We suggest you send your donation before June 10th, to receive without delay your tax receipt to enclose with your tax return.

If you are a company, every € 100 you donate to research represent only € 40 (tax reduction of 60 % on your donation up to 5 % of turnover ; if more, carried forward on the next five years – Tax code, Art. 238 bis).