

## RESULTS

Cerebral Palsy concerns 125 000 persons in France and affects four newborns each day. Children, teenagers or adults, they all experience motor problems necessitating rehabilitation for their entire lives. The ESPaCe survey led by the Fondation Paralysie Cérébrale is the first investigation of this sort aiming at giving an overview of rehabilitation in France.

### Why an investigation on rehabilitation?

All people affected by Cerebral Palsy experience motor problems and a third of them suffer from inability to walk. Additional (said « associated ») troubles regarding speech, vision or spatial orientation must be considered too.

All these troubles necessitate rehabilitation, motor or not, which is thus a big part of the people's lives throughout their entire existence.

So rehabilitation is important; but we lack studies and objective data on the subject. For this reason, the foundation wanted to conduct a large survey with the persons concerned and their families. This investigation is unprecedented at the international level.

### The investigation's major lessons

#### Physiotherapy is the pillar of motor rehabilitation

- General pattern: two 30-minute sessions per week, often carried out in private practice
- A pattern not always adapted to the person's situation (age, seriousness of the damage, expectations...)

#### Other types of therapy, like orthophony or occupational therapy, are insufficiently practiced

- Less than half of respondents get rehabilitation other than physiotherapy, while speech disorders, for instance, concern 62% of them

#### Patients express frustration with regard to rehabilitation

- One third of respondents experienced discontinuity of care, most often because of difficulties to find practitioners both available and trained in Cerebral Palsy
- The person's opinion is insufficiently taken into account when choosing which techniques should be used

### ESPaCe

or

Cerebral Palsy Satisfaction  
survey

- A national investigation conducted with people affected by Cerebral Palsy and their families
- Through self-administered online questionnaires
- Conducted from June 2016 to June 2017]

## Expectations regard

- Better training in Cerebral Palsy and new rehabilitation techniques for practitioners
- Better coordination among professionals providing care
- Increased involvement of patients in their own care

## We can thus consider that the patients' needs are only partially covered

- While motor rehabilitation (except for orthophony and occupational therapy) is usual, for an annual cost estimated between 200 and 300 thousand euros
- Only two thirds of the respondents consider themselves satisfied and acknowledge a positive impact of rehabilitation on their quality of life.

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## Motor rehabilitation practices in Cerebral Palsy in France: an overview

### 1- A prominent position for the self-employed

Self-employed physiotherapists hold an important position in motor rehabilitation, working with 46% of the persons concerned, 54% of the adults.

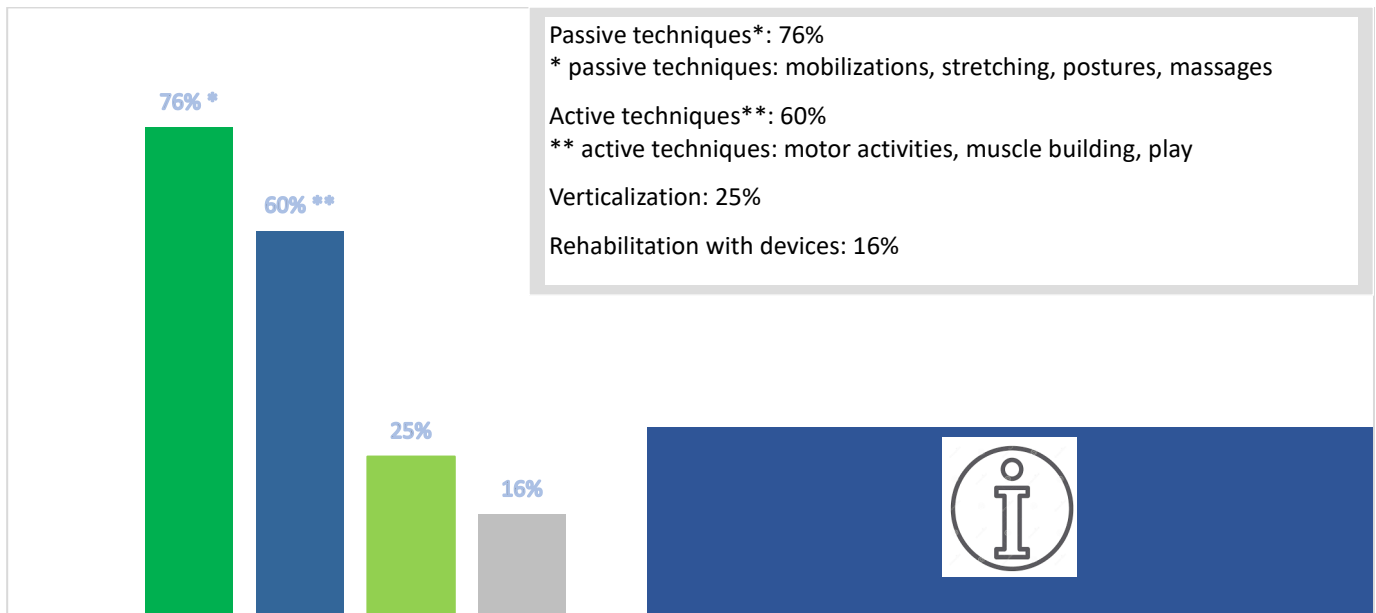
This statement is valid whatever the injury severity, except for the most affected patients, who usually get rehabilitation in their nursing homes or specialized care homes.

There are less coordination and exchanges between professionals when they are self-employed. It is especially true in adult care.

### 2- Care throughout the entire life

For most of the persons concerned, we observe continuity of motor rehabilitation sessions throughout their whole lives (68%).

### 3- Passive techniques are the most used



### How do physiotherapy sessions take place?

- Two 30-minute sessions per week, whatever the age and the injury severity. It is a specificity of the french model.
- Mostly individual sessions (81%), particularly for children and teenagers (more than 85%);

2-to-6 year old children are those who benefit the most from active rehabilitation techniques (81%).

We also observe:

- A disparity in the methods used according to the rehabilitation framework
- An identical distribution of the techniques, regardless of the injury severity

**4- The quality of the relation is the first criterion for patients**

Trust, respect and support from the physiotherapist are the most important criteria during sessions, whatever the age or the injury severity.

**5- Use of alternative or complementary techniques is not negligible**

It concerns 10% of all respondents, and 25% of 2-to-6 year old children.

Among these techniques, osteopathy is the first mentioned, by more than half of the persons.

**6- Pain is part of most patients' lives, but it can be relieved by physiotherapy**

Adults are the most concerned by chronic pain (75% against 66% for all respondents).

In most cases, physiotherapy creates a relief immediately or after the session. This beneficial effect is particularly notable in most affected patients.

**7- Motor rehabilitation has a positive impact on the patients' quality of life**

But this positive effect on quality of life is lesser on relatives, who have to devote time and energy to organizing sessions and accompanying.



LIGHT

Audrey Fontaine

Physiotherapist,  
CAMSP Jeanne Levy, Paris

These results raise many questions or reflexions on our « french model ».

- Sessions in private practice are advantageous in terms of convenience (proximity, flexible hours), but they have their limits: in particular, neurological rehabilitation necessitates a certain specialization of practitioners and sometimes adapted devices. Transmission and coordination between professionals are also more difficult, and not recognized as working time.

- Does everyone need care at the same rate, regardless of age or the nature of the damage? How to explain that sessions last 30 minutes twice a week? It is the minimum required by Social Security to reimburse physiotherapy acts.

- It is easier for non-specialized physiotherapists to put into practice passive techniques. But patients and scientific literature say that active techniques are more efficient, less painful, and that they make patients the actors of their rehabilitation. And physical activity is beneficial to all, affected or not by Cerebral Palsy.]

## Evaluation of perceived needs

**1- The first need concerns the humane or relational aspects**

Whatever the age or the injury severity, all people affected express the feeling that they have the right to ask for precisions and to be implicated in practical decisions concerning their motor rehabilitation.

They also have a need for exchanges and for a follow-up with professionals, and a person to coordinate all interventions.

**2- The main difficulties concern access to rehabilitation**

In particular, more than half of people with the most serious damages experience difficulties in finding a physiotherapist trained in Cerebral palsy.

**3- The main expectation is to receive other types of rehabilitation practices**

Expressed by 50% of respondents, this wish first concerns adapted physical activities, or longer physiotherapy sessions, using other methods (intensive rehabilitation, induced stress). Then we find alternative therapeutics like osteopathy or balneotherapy. But there are many obstacles, from lack of information to supplementary costs supported by families.

#### 4- Physiotherapy remains the key practice

It is indeed the priority of more than 80% of the respondents, followed up by ergotherapy, psychomotricity and orthophony.

#### 5- Expected improvements concern everyday life

It covers in priority preservation (if possible improvement) of functional capacities, and an increased autonomy in everyday life.

Another need expressed by families is to be able to act the best way with their child.



#### Determining satisfaction factors towards motor rehabilitation

- 1- The clinical profile of the person: injury severity, pain related to Cerebral Palsy
- 2- The organization of rehabilitation: coordination and training
- 3- The contents of the sessions: handling pain, information and objective setting

These two last points are thus prospects for improvements



**TESTIMONY**  
**Gaëlle Drewnowski**  
Expert patient, Lyon

Like other patients, I need lots of rehabilitation: 5 physiotherapy sessions in average per week to control pain and retractions caused by severe spasticity.

Although I live in a great city, I had to contact 52 physios to find 2 trained in Cerebral Palsy and available: physios are very busy with children, who remain a priority, and one alone cannot carry the burden I represent in his or her schedule. So it took me eight months to put into place a system adapted to my needs.

During this time, I had to settle for one or two sessions a week, which means handling pain by taking more analgesics and practicing as much as possible auto-rehabilitation.

Even if physiotherapy sessions can cause pain and fatigue (Cerebral Palsy makes us easily tired), I know too well the effects of a lack of sessions not to make it one of my priorities: retractions manifest again in 48h, and starting over is very difficult.

For me physiotherapy is essential: it doesn't produce the same effects than other methods that are yet interesting. Not to mention the obstacles one meets when looking for adapted physical activities: in spite of a medical certificate, I didn't find a fitness room (except for extremely expensive private centers) willing to accept me.

It is thus urgent that we succeed in revaluing sessions to engage physiotherapists to take patients with CP so we don't live with this permanent deficit.





LIGHT

**Pr Vincent Gautheron**

Physical Medicine and Rehabilitation, Saint-Etienne Hospital, SFERHE-SOFMER

Two factors determine satisfaction towards rehabilitation: its organization and the contents of sessions. These are thus the main areas for improvement.

– **The contents of sessions**

Expressed expectations carry precious information on treatments and exercises, and the construction of care with patients themselves. So interventions in which the patient-therapist relation is valued are under study, as practices inspired by research progress, more educational, with more intensive sequences, in which the patient becomes the expert of his or her rehabilitation.

It implies that initial and in-house training for physiotherapists evolves, that collaborative practices are favoured, and that networks with professionals are put into place.

– **The organization of rehabilitation**

We must also improve coordination between professionals.

Avenues for reflection regard the creation of regional resource centers, the installation of local teams and the modelling of monitoring techniques for the different kinds of Cerebral Palsy. Finally, valuing the professionals' commitment in coordination and collaboration activities is another key aspect for future improvements.]

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## Expected improvements

**An important expectation expressed by the respondents is to increase the number of physiotherapy sessions, from two to three per week, and above all to raise their duration to 45 minutes.**

Other improvements were asked for by the respondents:

- improving training in Cerebral Palsy with its specificities for physiotherapists (80% on average); the persons with the most severe damages have the highest demands
- improving information on care along with recommended exercises (75%). This demand was expressed by children and teenagers' parents especially
- improving communication between professionals (70%), particularly in private practice
- constructing care with the person (66%), especially for the adults
- improving coordination between professionals (57%), particularly in specialized institutions
- improving pain management (54%), particularly for teenagers and adults.

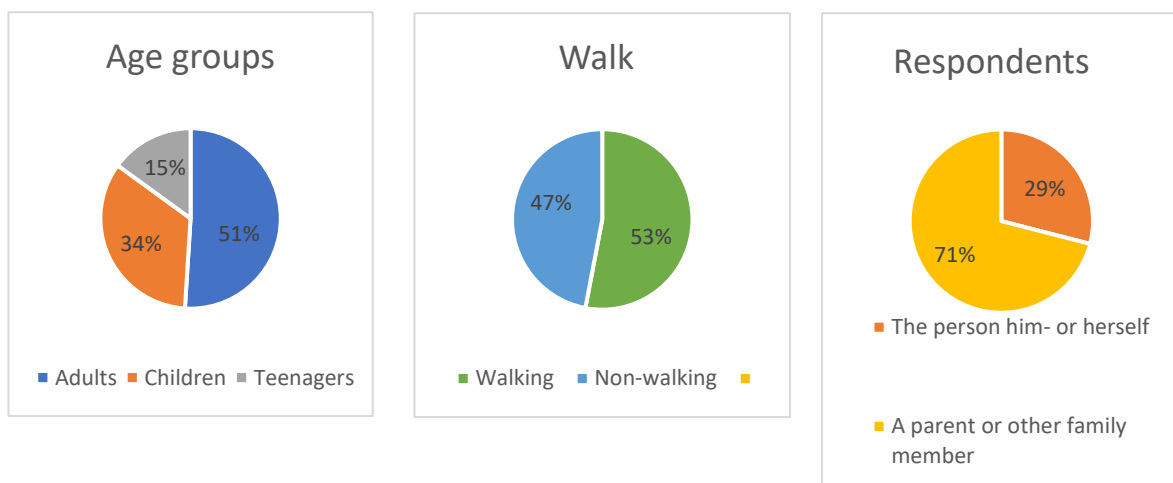
## Areas for change

- 1- Organizing rehabilitation around the needs of families and professionals: coordination, information, formation
- 2- Developing recommendations and clinical good practices based on scientific evidence to harmonize the quality of care
- 3- re-thinking pricing of rehabilitation acts to take into account coordination needs and new rehabilitation modalities in everyone involved
- 4- developing research in rehabilitation

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## ESPaCe Study in figures

More than 1000 questionnaires on persons affected by Cerebral Palsy were collected and analyzed. 91% of these persons were getting physiotherapy sessions at the moment of the inquiry.



### TESTIMONY

**Geneviève Geyer**  
**Fondation Paralysie Cérébrale**

To manage this project, we worked in tandem: Maria Bodoria, in charge of scientific coordination, created the group and managed the scientific aspects of the project, while I took care of the organization and the follow-up. That means, among other things, coordinating the actions of the steering committee, whose members came from various horizons, and working with the service company that realized the investigation. We selected Kappa Santé after a call for proposals among four candidates.

The main difficulty was to get to the persons concerned so they participate: as a research foundation, we are not in direct contact with them. So we had to work with organizations that represent them, and to devote significant effort for communication. Another difficulty was to recruit teenagers: at their age, handicapped or valid, they have other worries! But everyone's efforts paid off and we are proud of the work accomplished.



## Steering committee

### Patients representatives

- Julia Boivin
- Gaëlle Drewnowski

### Representing families

- Dr Eric Bérard (FFAIMC)
- Anne-Catherine Guenier (association Hémiparésie)

### Representing learned societies

- Pr Sylvain Brochard (SFERHE, SOFMER)
- Pr Isabelle Desguerre (SFNP)
- Pr Vincent Gautheron (SFERHE, SOFMER)
- Yann Le Lay (CDI)
- Philippe Toullet (CDI)

### Representing field professionals

- Nathalie Chauveau
- Dr Gwenaël Cornec
- Audrey Fontaine
- Dr Michel Thétio

### Representing the Fondation Paralysie Cérébrale's scientific council

- Dr Eric Bérard
- Dr Javier de la Cruz

### Global coordination, Fondation Paralysie Cérébrale

- Dr Maria Bodoria
- Geneviève Geyer

### Research organism, Biostatistician

- Kappa Santé





## Read and heard during the investigation

### NEXT STEP 2019/2020

Following its referral by the FFAIMC (Fédération Française des Associations d'infirmes Moteurs Cérébraux) and 4 learned societies (SFERHE, SOFMER, SFNP and CDI) at the instigation of the Fondation Paralysie Cérébrale, the High Authority of Health included in its work program 2019 the development of good practices recommendations on rehabilitation for persons affected by Cerebral Palsy.

« Current care for our child stops at 16-year-old, after there is no possibility of care in our department »

« I started individual tai chi sessions, but I had to stop: it was too expensive »

« **30 minutes is too short to remove and put back my feet splints** »

« When I ask for a break, I get no answer except « take a holiday! »

« I would like to be trained in massages I could practice at home to help my daughter in her relaxation and take care of her legs (that are in splints 24h/24) »

« My sister would be very unhappy far from her family, two disastrous attempts in her youth showed it. We live in the countryside, nothing is close »

« When I was little, I was traumatized by pain caused by posture »



## Thanks to our partners and supports







FONDATION  
PARALYSIE  
CÉRÉBRALE



To make research research progress, we are counting on you!



April 2019

Fondation Paralysie Cérébrale

Dear donors, dear friends,

It is with great gratitude that I write to you today. You are part of donors and benefactors of the foundation and as such you deserve all our thanks.

Thanks to your donations, we have funded for 14 years more than 80 research works that already led to significant progress.

Despite these progresses, Cerebral Palsy still affects one newborn every 6 hours, and it is a long road to improve lives of those living with this handicap.

In 2017, we conducted an important study to give an overview of motor rehabilitation in France and to identify areas for improvement. The **ESPaCe** (Cerebral Palsy Satisfaction) **Survey** encouraged us to launch a large-scale call for proposals in 2018 to fund a broad research project dedicated to rehabilitation.

This **important scientific project**, the CAP project, unique in its duration and its budget, will allow us to validate the interest of intensive motor rehabilitation in newborns, among other things.

Thanks to new techniques and new rehabilitation protocols, we can hope to improve the motor prognosis of children with Cerebral Palsy, along with their autonomy and quality of life in general.

As you can see, we are now taking major steps, which means great improvements for persons affected by Cerebral Palsy. You make it possible when you give money for research.

Help us to maintain this hope and to offer a better future for our children and their families.

In advance, I am thanking you.

Dr Alain Chatelin

President