



October 6th, 2021: to mark World Cerebral Palsy Day, a strong call for action was sent to reduce glaring inequalities, improve the treatment of CP, and ultimately the condition of the persons who live with it. This white paper, addressed to public authorities – and to all –, is the result of more than one year of collaborative work led by the foundation.

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- 1- A call for decision-making, Pr Marc Tardieu



President of the steering committee, he wrote the summary of the white paper on Cerebral Palsy

« helping to make a decision » is one of the main missions of a white paper. Pr Marc Tardieu retraces the path that led to the publication of the Cerebral Palsy white paper.

Why was this white paper written?

To understand the origin of this initiative, we must go back to ESPaCe, a study on motor rehabilitation the results of which were published in 2019. This survey, which 1000 people answered, revealed an important issue: only 25% of those surveyed said they were satisfied with their rehabilitation !

The awareness raised by this study led us first to write the Rehabilitation Charter, a tool for dialogue and commitment between the professionals and their patients (and families) signed by public authorities and learned societies. Good practice recommendations followed, which are being



Interview with Pr Marc Tardieu

Honorary professor of the universities, Pediatric neurology

Former director of an Inserm unit, Vice-president of La Fondation Paralysie Cérébrale

Many thanks to all without whom this white paper would not have seen the light.
The steering committee
The coordination and animation team
Participants in working groups

finalised by the French National Authority for Health and should see the light at the end of 2021.

But we still felt the need to gather more information on what life with CP is like, and what can be done to make a difference.

That is how the principle of a white paper became imperative. It is more than time for us to overcome the frustrations caused by inadequate treatments and to draw the lines that will conduct politicians and administrations to make decisions.

How was this approach expanded ?

The basis of this work rests on what people told us. There were many involved: those living with CP, their relatives, but also professionals, carers and researchers in different fields.

In order to collect their experience, we worked with a consulting firm that used its « collective intelligence » method to facilitate four working groups. Summaries were made in common at the end of the sessions then approved by all participants before being sent to me. These statements served as the basis for the white paper, which is thus a summary of what the people involved had to say.

How were the workshop topics chosen ?

We organized the workshops following the National Health Strategy for 2018-2022:

- implementing health promotion strategies, including prevention

- fighting social and territorial inequalities in terms of access to health

- guaranteeing quality, security and adequacy of care

- innovating to transform our health system, reaffirming the role of its users

From these workshops emerged transversal topics and pillars representing the important points that stood out (see the box below).

But this initiative must not stop here. There are still things to work on within the white paper, which should lead to a national strategy using measurable objectives.

FONDATION PARALYSIE CEREBRALE

These works, built in close collaboration with the individuals involved, allows us to define the main priorities of a road map leading to significant progress in supporting people with CP at all stages of life.

Five transversal themes to reflect on

- 1) Confidence and competence centres !
- 2) Who is in charge of ensuring the quality and the adequacy of care ?
- 3) From school to work: adapting to singularity rather than rejecting complexity
- 4) Social and territorial inequalities compounds the problems faced by disabled people
- 5) Scientific innovation, evaluation practice, progress for all

To whom is the white paper ultimately addressed ?

This paper has three « targets »:

- the departments concerned: health and disability of course but also work, education, higher education and research...

- media, since we still have to make CP and its specific issues known to the greater public

- those who are already sensitized or concerned and willing to know more.

The paper was distributed for the first time on October 6th, on the occasion of the World Cerebral Palsy Day, and we continue to disseminate it. In order to achieve this, we can count on our partners: learned societies and associations.

What are the main messages this white paper wants to share ?

The first message, and it is key, is that CP is not just about health or disability. Living with CP has implications for schooling, work, participation in society etc. The confidence and competence centres we call for should give information on all these issues.

Next, it is urgent to look after teenagers and adults with CP. Too often, we have tended to let things go after infancy, yet the more you grow old, the more difficult life with CP becomes .

The third message concerns what isn't visible but has huge implications for the persons' lives: the « invisible » or

« associated » troubles, as we sometimes call them, which make cerebral palsy so special, not reducible to motor issues. Cognitive troubles for instance have very important effects on schooling or work. We don't talk enough about them, and we don't do so properly. We must get over categories and start with people, give ourselves reachable goals, create small flexible structures, more adapted to personalized care.

The fourth point is prevention, in particular of premature birth, which is a factor for occurrence of CP. It is not just a health issue, it relates to women's working and even living conditions.

Finally the last message is about research and training. We need more therapeutic trials in the field of rehabilitation, which is a relatively new research field.

What will follow this work ?

Now we must move to implementation, by spreading this paper, transforming it into something useful leading to decisions. It is a big communication and lobbying effort with the general public, for which we will mobilize all our forces and move forward with our partners.

The seven pillars for the development of a national action strategy

- 1) Enable everyone to participate in society and to live in their own home
- 2) In every department, create a competence and confidence centre for persons with CP

- 3) Strengthen the prevention of CP and premature birth
- 4) Adapt the care system to the specificities of CP based on the new recommendations of the French National Authority
- 5) Support rehabilitation sciences by establishing a partnership between patients, families and researchers
- 6) Improve training in the field of CP for health professionals, without territorial inequalities
- 7) Adapt educational and vocational guidance to the complexity of CP

2- How can we make these voices heard ?



Interview with Christèle Kandalaft-Cabrol
expert parent of a child with CP

Participant in the working group « Innovating to transform our health system, reaffirming the role of its users »

You accepted to participate in a working group, what was your motivation behind this?

The first motivation was my daughter and all her friends living with CP: how do we ensure respectful living conditions for them while CP is

already so much to bear on a daily basis ? How can we make all these voices heard ?

Representing parents in the steering committee gave me a chance to speak about the difficulties we, patients and families, face every day. Since in practice, our care pathway really is an obstacle course.

This collective work, in the committee and in the working groups, allowed us to gather all arguments to sound the alarm for the government, to say how urgent it is, that we must help and act quickly.

What did you learn from it ?

It was a very enriching experience, and I thank the foundation for having allowed me to participate in this project. I appreciated the opportunity to exchange and share experiences with persons with CP, families and professionals from the medical world. Observing how complementary we are and seeing ourselves moving in the same direction, it was two very unifying factors.

The second pillar of the white paper is called « in every department, create a competence and confidence centre for the persons with CP ». How important a topic is this?

I am a part of several family networks and I see many of them exhausted from fighting for everything:

- unsatisfying listening leading to delayed diagnosis: patients sometimes have to wait one year for their first hospital appointment
- ignorance of CP and its troubles, which can lead to

major diagnostic errors

- trouble finding therapists adequately trained in CP as well as quality structures to welcome our children

- ignorance of rehabilitation methods and therapies from professionals... Families are on their own, they must get information themselves while they already have the diagnosis to digest, its effect on everyone, the siblings to manage. Very often, unfortunately, this lost time represents lost chances for the children.

The seventh pillar is « adapt educational and vocational guidance to the complexity of CP »: in the field of schooling, which concerns you the most, you report many difficulties.

Families mention many failures: accessibility problems in schools, considerable lack of human resources (lack of personal assistants, « auxiliaires de vie scolaire » AVS, or mutualized ones), training issues for these AVS and for the teachers, a small number of hours granted by the MDPH (departmental centre for persons with disabilities), lack of support... Families are in a situation where they have to explain what CP is to the school staff, to coordinate exchanges between the different participants, even to find training for teachers and AVS at their own expense ! In the case of our daughter, for instance, we had to recruit a neuropsychologist from the first year of kindergarten, to intervene at school but also to teach her AVS and her teacher

about cognitive and behavioral difficulties.



Every year we must fight to get support: for all hours having an educational content, but also for social times (transition, recreation) that are so important for participation and socialization.

Why, when it is possible, are our children not entitled to the same number of school hours than other children their age ?

APF FRANCE HANDICAP

What was realized for « rare » diseases or disabilities (reference or competence centres, training, research, support networks), should be possible to implement for a pathology like CP, characterized – as we can read in the white paper – by its overall incidence, the extreme diversity of its motor or associated consequences, extending to polyhandicap, and the evolution of their impact throughout life.

SFNP
Société française de

neurologie pédiatrique – French Society for Pediatric Neurology

While knowledge has progressed over the past few years, the inadequacy between these theoretical progresses and the treatments proposed to the patients only grew. Moreover, there is great heterogeneity in terms of access to care within the French territory.

3- Shifting the paradigm

Promoting innovative therapies with a proven track record and changing the care system to include them are two major issues. For Denis Jacquemot, occupational therapist, the white paper must serve this necessary evolution.



Interview with Denis Jacquemot
occupational therapist
L'Escal, Pediatric Rehabilitation Unit, Lyon.
French national reference centre for childhood stroke
Participant in the working group « Innovating to transform our health system, reaffirming the place of its users »

Fields like occupational therapy, while an important part of the treatments for children with CP, are rarely visible in big projects. Is it what led you to join the working groups of the white paper ?

Indeed I was solicited by the French national association of occupational therapists to be the voice of our discipline. Occupational therapy has its place in many studies in Canada or Switzerland, but this field is still limited in France, while research on this topic needs to be developed.

But my main motivation comes from my work. In particular, my missions for the reference centre for childhood stroke made me familiar with innovative therapies such as HABIT-ILE (Hand and Arm Bimanual Intensive Therapy Including Lower Extremities), confronting me with the limits of the system.

Can you explain it ?

These methods, which prove their effectiveness every day, are based on neurosciences but also on the involvement of families so the benefits of the treatment sessions become part of everyday life. We all believe in that. So families must be included in these studies on methods, but then we face difficulties:

- research in rehabilitation is in the process of structuring itself, teams are still « young » and including a further actor is therefore complicated
- research and validation of techniques to build recommendations

require a specific methodology: it is a new culture to be transmitted to the parents, which takes time – finally all that costs money.

But it mustn't make us lose sight of the objective, which is helping families with these new approaches centered on important objectives, significant for children, as well as supporting this emerging research field around psychosocial and environmental aspects of CP and disability.

What means could be implemented ?

I could summarize all that by saying it is a paradigm shift.

We are witnessing a transformation of the support received by children through these new intensive therapies, grouped in short-term courses that disrupt the current organization of care. Putting research into action is an enormous challenge that mobilizes several levers:

- training of professionals (initial but also continuous training for therapists already practicing)
- structuring teams: today care is too fragmented and certain competences or expertises are lacking
- and finally the adaptation of care.

The goal-oriented approach, with at its heart the concerns of children and families, leads to a more specific and individualized follow-up, far from the standard care we know. Let's add that the health care system was thought in a holistic manner around the disability – as if it had a single

face, the consequence being that medico-social care doesn't always take into account the specificities of CP. We need to develop competence centres and/or reference centres, at the service of families, which would also allow us to put research into action. Appointed coordinators are also a strong expectation of parents, who do not know where to turn, who sometimes hesitate to ask and remain waiting while their active participation is needed.



Rehabilitation is in the process of evolving, from an organic approach to one based on the child's participation and achievements in regards to his or her activities. Accompanying parents to this model could be the role of occupational therapists, often at the crossroads of different fields: we need to go beyond the strictly motor aspects, which can induce anxiety, and to consider instead the needs of children in their daily lives, in relation with their environment. It is the purpose of rehabilitation.



Overview:
Mathieu Cabrol

Consultant at Stanwell Consulting
Facilitator in the working groups
Father of a child with CP

The pandemic forced us to adapt the organization of the working groups (face-to-face sessions, that we usually prefer, were not possible), but aside from that we didn't really change our methods. When I read the project – an approach based on the facilitation of four working groups teaming together professionals and people affected by CP, it seemed obvious to me that the implementation of our method, which I use for projects in other contexts, was the right solution.

We often speak of « design thinking » to describe these facilitation methods, I prefer to use the expression of Lorraine Margherita (who co-facilitated these working groups with me), who speaks of « collective intelligence ». The objective is to create conditions for exchange between all participants, to facilitate the group in a way that everyone can share – sometimes confront – ideas. In the end the collective result is way richer, more creative and relevant than the sum of the contributions we would have

gathered separately.

The size of the project, the number of persons mobilized, the « online » mode and the total length of the workshops (spread over several months) would be enough to make this experience atypical and thus enriching on a professional level. But what made it really unique, is the involvement and the emotion of the participants, including me.

My regular customers, the ones I usually have in front of me in workshops, are bankers and insurers for example. They can be very involved, but still, a professional distance remains, on my part (the facilitator) even more. In this case it was a whole other story. There was no distance for the mother of a child living with a cerebral palsy, for a person who has been fighting his or her disability every day for more than 30 years. It was difficult for me too: I have a daughter who lives with CP. The intensity of emotions (sadness, hope, anger, frustration, pride, rebellion), the kindness and listening skills of all participants, gave the debates a dimension I never experienced in a professional context.

4- The psychological aspects of CP are too often forgotten



Interview with Amélie Guigou
clinical psychologist living herself with CP
Participant in the working group « Health promotion policy, including prevention »

Affected yourself by CP, you see patients who live with this disability. What encouraged you the most to participate in the white paper ?

Both, both are related: today, with my experience as a psychologist, I can analyse what I went through having been given the keys. Looking back, I realize that the psychological aspects of my condition were not very well taken care of.

Rehabilitation is organized quickly, framed by structures like SESSAD* of CAMSP**, but we don't always know what it means: it is a long learning and acceptance process for families and for the persons themselves. And clearly we lack a space to discuss it.

* SESSAD: service of specialized education and home care

** CAMSP: early medico-social action centre

Although CP is not an acquired disability, how do you explain this « learning » time (learning of the disability) by the persons themselves ?

In the case of CP (in the absence of intellectual disability, which is the most common), especially when the persons attend regular schools, they often navigate in a hybrid space, neither in one world nor the other. They have a vague awareness of their disability, which isn't without consequences for their daily lives or their learning of relationships with others.

For instance, we do not integrate associated troubles or fatigability in our perception of the pathology. I wasn't aware of my problems with spatial awareness and when I lost myself in the subway, I thought it was because I was «being silly”.

The integration of disability doesn't happen like that. Often there is denial, and – paradoxically – the more the deviation from the norm is reduced (when you're « almost there », to paraphrase the title of Alexandre Jollien's movie), the more this denial is strong.

What are the consequences ?

Associated troubles can have important consequences for the children's life, by increasing feelings of anxiety and insecurity for instance: you are not calm and collected when you are afraid to get lost. This anxiety adds to a pathological insecurity caused by a difficult birth. We really need to train psychologists so they become more aware of

these specificities, and to make them understand that psychological care is as important as rehabilitation.

Also, we often observe that children protect parents from their disability, psychologically I mean, because they see them suffering. It is thus essential to have discussion spaces for children and for parents.

It is consistent with the fact that the persons need to be – and to make their desires – heard.

Indeed. In educational or professional guidance, there are situations where grieving is necessary, but in most cases adjustments would make the project possible. Sometimes it only requires that fatigability and other difficulties are taken into account: at some point during my studies, for instance, I got assistance for taking notes, my grades increased from 11 to 15 ! When you consider the difficulties, you enable an easier access to studies: we must listen to the persons' wishes before we close doors to them.

The same for human support: again, we must start from the person's wishes, they are not whims ! With human and material support, you can free time for your professional and relational life, which improves your participation in public life. Everything that allows the persons to remain at home really makes a difference. In an institution, one's decision making power is very limited, you find yourself faced with contradictory demands: autonomy, but in the frame of the institution. You must be a

“truly disabled » person.

Autonomy lies in decision making power, which life at home makes possible. When it is not doable, it is necessary that the persons can fully participate in decision making in the institutions. It requires the proper training for therapists and carers.

SOFMER

French Physical and Rehabilitation Medicine Society

Seven priority pillars emerge, some having in common the necessity of strengthening

scientifically established knowledge, (...) of sharing and disseminating it to professionals and families.

Such a strategy requires the development of specific training and the promotion of proper rehabilitation sciences, as well as an ever closer partnership between patients, families, researchers and of course clinicians.

5- The treatment of CP needs proximity, there is urgency !



Interview with Laure
Nitschmann

Development Director at
Institut Motricité Cérébrale
Mother of a young adult
with CP

Participant in the working
group « Guaranteeing
quality, security and
adequacy of care »

You participated in the working group in two respects, as the mother of a young adult with CP and as a professional in training. You advocate for more proximity between the different actors.

Yes, more proximity and exchanges between the different reception, rehabilitation, research and training facilities. This is why I find this white paper very important : CP and its specificities required us to do something.

Despite all the hard work, CP remains little known, which is not the case in other countries. We need to accelerate communication so families, adults and professionals know where to turn for better support. For instance, with the health crisis caused by the COVID-19 pandemic, many professionals called us (at the

institute) since it was impossible for them to find help in ordinary psychiatric consultations for the patients they were taking care of, who experienced additional difficulties due to lockdown measures. Finding specialized facilities remains an obstacle course.

So it is urgent to create relay points, which would work as crossroads between hospitals, private practitioners, institutions, training facilities... in every department. We need a care network with meeting points where it would be possible to guide the persons with CP. The issue is to meet local needs, something a unique resource centre couldn't do.

INSTITUT MOTRICITE CEREBRALE

A special effort should be made on training so we have competent professionals able to act in different situations – private professionals in particular should have access to training. The objective is to offer access to innovative pedagogical methods to meet their needs and demands, which are repeated short-term courses based on the analysis of professional practice, and regular support.

The second pillar of the white paper is about creating a competence and confidence centre in every department.

It really is a priority. These last 15 years were enriching: the plurality of offers made progress thanks to the efforts of actors like la Fondation Paralysie Cérébrale, the French Cerebral Palsy Research Network or the Institut Motricité Cérébrale, thanks also to the expertise of parents or professionals. Today we see the emergence of new methods. For all that it is time to organize information.

To be efficient, we must rely on what exists already, on the local actors in the field, to build a big information and care network. There is a great richness in our territories, which we are not always aware of. So I believe it is urgent to draw up an inventory of the existing resources. Next, the competence centres should be attached to institutions or hospitals so they are not isolated structures and can have the right information at the right time to be at the service of the persons' inclusion.

As a follow-up to this topic, the sixth pillar stresses the need to have better trained professionals and to reduce territorial inequalities. What is your approach to these questions ?

Initial training isn't enough to know how to help persons with CP. Professional training is essential if we want to give professionals the means to act in a relevant way with patients, children or adults, in situations as complicated as cerebral palsy. A wrong response from the professional can cause an additional disability, it is not without consequence for the

individuals.

Today we can use the new tools set up to continue training in order to encourage more professionals to undertake training. The continuing professional development (CPD), dedicated to health workers, and the personal training account (compte personnel de formation CPF) are individual tools available to professionals. It is thus indispensable to steer a training offer in collaboration with the regional health agencies (agences régionales de santé ARS), which have a good knowledge of their territories. Together with the French National Authority for Health, the ARS could help disseminate information to a great extent.

Training at the institute is organized around three different questions:

- technique, know-how and interpersonal skills
- analysis of practices, very important
- the value of informing and exchanging with families, of having therapists who give information to the teams on the field and the other professionals so they can support the child or the adult properly.

In medico-social centres, we developed a three-part training including feeding, management of the daily consequences of cognitive troubles, and movement. These modules were deployed in territories. The evaluation surveys we conducted showed improved practices and possibilities to better adapt to the needs of persons with CP.

The transformation of the medico-social offer and the necessary inclusion of people with CP force us to implement an ambitious training plan for professionals and carers in the broad sense. Environments – from school to housing – must be transformed to be better suited to the persons' needs.

We observe that multidisciplinary private practices develop: these structures are very interesting but they are few in number and too often dedicated to children only. For adults, it is almost impossible to find private therapists.

We've reached a favorable time for the different actors to coordinate in order to develop local solutions for everyday life, and more specialized ones for the issues requiring particular expertise.

It is the definition of « training »: « to create a complex set of elements by arranging them ».

SFERHE

French-speaking society for studies and research on childhood disabilities

The field of rehabilitation involves many medical professionals, in rehabilitation and in the socio-educational sphere with a specific training in this kind of support.

The current disparity of resources through the territory is obvious: there is no doubt it leads to lost chances for many persons suffering from cerebral palsy, struggling to find

authorities in this field.

6- Reducing territorial inequalities would also allow to reduce risk factors



Interview with Dr Clément Chollat

Neonatologist pediatrician, MCU PH, Hôpital Trousseau, Paris

Member of the SFMP's board of directors, member of the steering committee of the white paper, participant in the working group « Health promotion policy, including prevention »

Prevention, diagnosis and early care are essential to prevent CP, or its severity. Dr Clément Chollat, neonatologist, tells us about what remains to be done.

Your specialty puts you in the front line in regards to the prevention and the follow-up of CP in newborns. We understand that you are involved in this white paper.

Indeed, I am involved at two levels: as a member (in the

board of directors) of the SFMP, a learned society solicited by La Fondation Paralysie Cérébrale for this project, but also because my work as a researcher was about magnesium sulfate, the only medicinal solution that exists at present to prevent the occurrence of CP (it is given to pregnant women at high risk of premature birth). Today new research is about other candidate molecules because of their neuroprotective effect, but we still lack many of the tools needed to achieve that.

COLLECTIF HANDICAP

Every disability is different and requires a specific response, an adapted and personalized everyday life and life course making possible unique responses to the different situations which, regarding cerebral palsy, remain little known and stereotyped.

Precisely the third pillar of the white paper is about « strengthening the prevention of CP and of premature birth ».

We know that premature birth is a major factor for the occurrence of CP, it is thus essential to try to prevent it. It is what we call primary prevention. In France, we can consider ourselves lucky in regards to the quality of prenatal care, but there is still progress to be made, for instance for women in precarious situations who, due to difficult life situations, can be at higher risk of premature

birth. There is also unequal access to care (including follow-up care) in the territory, it is an important topic to consider if we want to improve further primary prevention.

Progress must be made also in regards to the child's period of hospitalization. An important part of the difficulties is caused by infectious, digestive and pulmonary complications that occur after birth; if we manage to reduce neonatal morbidity during hospitalization, prevention will improve. Everything that enables us to respect the baby, his or her rhythm, to reduce stress or exposure to uncomfortable, even painful acts, improves his or her future. In this regard care related to development, centered on families, is essential in neonatal units, and must continue after hospitalization.

Protecting the developing brain requires the implementation of various actions before, during and after birth, and it would be time – in 2021 – to offer national recommendations in matter of neuroprotection for vulnerable newborns.



Preventing complications also requires improved monitoring and early care for children. Today we manage to save smaller newborns, who are thus at higher risk and need special care. Unfortunately,

care facilities like CAMSP (see above) are often saturated, with waiting times sometimes of several months !

You observe, like many, that the difficulties are not the same throughout the territory.

Yes, the problem of availability is not the same in all regions. But the gaps we observe are likely to persist. We lack beds, we lack carers, and this can lead to very difficult situations. Do we know how much we endanger a very preterm infant, so small and fragile, when we have to move him or her to another city, sometimes separating them from their twin ?

We are developing ambitious and specialized research programs, but first, it would be good if we had the means to provide proper care in our cities and our hospitals.

SFMP

Société française de médecine périnatale – French Society of Perinatal Medicine

Early care is key. Waiting lists to access the existing structures like CAMSP get longer every year. It is not rare that the waiting time for care after the first contact exceeds one year. In 2021, rehabilitation must be individualized and adapted to the patient, to his or her problems and to their families.

You also speak about the gaps

in regards to training.

A lot must be done in this field. There is insufficient training around neurodevelopment. CP is not in the curricula of podiatry in the second cycle of medical studies ! Yet certain children will develop CP without risk factors and « escape » the early hospital follow-up: it is thus necessary

that general practitioners and pediatricians in private practice are able to diagnose it.

Another thing we have to improve is communicating with the general public. If families were sensitized, they would be able to take into account the risk factors, we would improve the diagnosis

and the treatments.

Clearly the current methods are not sufficient, so we have to offer something else. For that, we need expert patients and parents. Also, it is imperative that the white paper triggers actions and that the departments concerned take up the issue.



Overview: Geneviève Geyer

Project manager at La Fondation Paralysie Cérébrale
Coordinator of the white paper's working groups

This white paper was written from the work done in collaborative workshops, which teamed together persons with CP, parents, and professionals with different profiles.

These workshops were facilitated by Stanwell Consulting following the method it developed.

The process, started in early 2020, had to be interrupted because of the lockdowns, then resumed in September 2020 in a format suitable for the situation: workshops were conducted via videoconference.

Participants received in advance stimuli and questions to prepare them for the theme chosen. Their participation was remarkable, resulting in very lively exchanges: not everyone agreed !

But what came out of every workshop and became the basis for the written paper is the result of a consensus, drafted during the session and approved by all participants. These syntheses are published as an annex to the white paper.

Partners of the white paper

