WHITE PAPER ON CEREBRAL PALSY

All over the world, as in France, national action can no longer be evaded or postponed.

ENGLISH TRANSLATION

Would you like to go to the cinema tonight?

I would have loved to …but I can't!
I need to book my specialised taxi two weeks in advance.

Have you had your mammogram yet?

No! The radiology practice was not wheelchair friendly.

CALL

October 6: A Call to Action

World Cerebral Palsy Day

Would you, the reader, accept this? It is the lived reality for people like us with cerebral palsy, and it is situations like these that cause our disability.

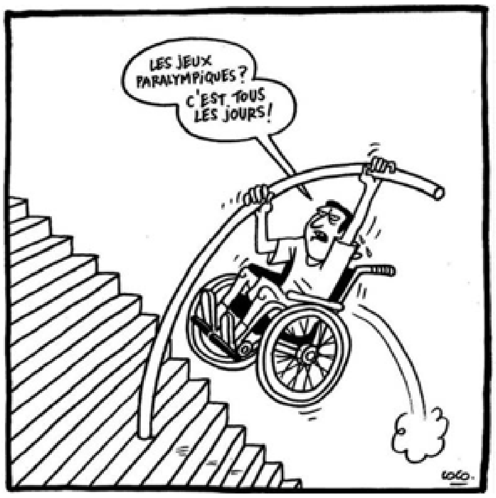
There has been undeniable progress in recent years: medical advances, an increased general acceptance of disabled people, and improved participation for disabled people in society...

But in 2021, access to basic rights remains restricted, and this continues to limit our independence. For those of us who depend on daily human support, or ongoing rehabilitation, this lack of resources is a barrier that prevents us from realising our potential and participating fully in society.

In this Paralympic year of 2021, athletes with disabilities are again in the limelight; cameras are focused on the Paralympians and their seemingly superhuman abilities. But for the majority of people with cerebral palsy, finding a physiotherapist, organising home help, or ensuring dignified living conditions are feats that require similar levels of dedication and energy as participation in any sporting competition. These actions, which should be so easy and straightforward, are instead like marathons that people have to run every day; and this raises the questions: do we not have the right just to be an ‘ordinary’ person with disabilities? Why do we need to be superhuman just to achieve an acceptable quality of life? Even today, in a society that considers itself inclusive, it is still people with disabilities, and their families, who make efforts, and even sacrifices, to adapt to their environment.

Although the 2005 Disability Act established the theoretical legitimacy of a place in society for people with disabilities, in practice enjoyment of full citizenship depends on your circumstances and where you live: the region, if it is urban or rural, if it is an institution or your own home as well as what support is available to you.

Cerebral palsy is diverse condition that is associated with a wide range of motor



Paralympics Games?
It’s every day!

disabilities and other associated disorders. Despite this variation, the care offered to those with cerebral palsy is rarely tailored to their needs and, as such, leaves many people side-lined. As a community, we no longer wish to be satisfied with a one-size-fits-all answer.

Would you accept someone else deciding what is important to you? Would you accept not having any say about the most intimate aspects of your life? Should you be treated like a child simply because you are in a wheelchair? Or overlooked because your speech is difficult to understand? Such 'small' acts of abuse, like these, occur daily for thousands of people with disabilities. Even if our generation is benefiting from hard-won progress, we cannot be satisfied with it; we owe more to the next generation.

This White Paper is a call to action and an effort to outline the features of a truly inclusive society. The ideas expressed here concern not only those with cerebral palsy but everyone, because the real question is how can we live together? How can we respect the needs, desires, strengths, and weaknesses of each and every one of us?

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LYON

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THE 7 PILARS OF THE WHITE PAPER

This summary prioritises seven action points that should serve as pillars in the development of a national strategy to support and include people with cerebral palsy:

1. **Enable everyone to participate fully in the home, social, and private life of their choice.** Improve pay and conditions for care assistants of children with disabilities, support those living in the community and clarify the regulations for sexual surrogate partners.

2. Create **centres of excellence** to provide accurate and reliable information and support for people living with cerebral palsy in each region. They should also coordinate with each other on a national and international basis.

3. **Strengthen the provision of pre- and perinatal preventative treatment** to reduce the incidence of prematurity and avoidable cases of cerebral palsy.

4. The care system needs to adapt to recognise the **range of individual variations in cerebral palsy symptoms.** In France, for example, this should be in line with the 2022 recommendations of the HAS, the French national health authority (Haute Autorité de Santé).

5. **More research is needed into rehabilitation** methods and techniques. This is not just a question of funding, patient-family-researcher partnerships are required.

6. **Increased training to raise awareness about cerebral palsy** and support health professionals regardless of where they are based. Everyone should benefit from the progress of research!

7. **Educational and vocational guidance should be adapted so that it can respond to the complexity of cerebral palsy.**

**ALL OVER THE WORLD, AS IN FRANCE,
NATIONAL ACTION CAN NO LONGER BE EVADED OR POSTPONED.**

FOREWORD

In France, every 6 hours, a child is born who will have to live with cerebral palsy. Numerous parents look abroad to Europe, or even the USA, for solutions and responses that they cannot find at home. The October 6th 2021 Call to Action has shown how slowly the necessary changes are happening, how closed society is to people with disabilities, and how little cerebral palsy is understood.

The time has come to start addressing this issue, and to question the national public health strategy through the eyes of those with cerebral palsy. The *Fondation Paralysie Cérébrale* and all its partners have, therefore, set the ball rolling with this White Paper.

We would like to express our gratitude to Marc Tardieu, chairman of the Steering Committee and author of this White Paper, to Jacques-Joseph Orvoen, Mathieu Cabrol (Stanwell Consulting) and Lorraine Margherita for leading the workshops, and to Geneviève Geyer and Nathalie Genès for the coordination. This report is the result of a collective effort and represents a common voice from all those who participated in the workshops or in the steering committee, including people with cerebral palsy, families, professionals, researchers, associations, learned societies and international experts.

How can we thank them, if not by loudly carrying forward their message, and by inviting government and public authorities to commit themselves to a dialogue that will lead to answers?

The common message is simple:

- A demand for **improved participation in society** and in daily life and respect for the right of people with cerebral palsy **to make decisions for themselves**.
- A demand for **skills:** resources are needed so that healthcare and other professionals can learn about the complexity and diversity of cerebral palsy, how it is a life-long condition that evolves, and the dynamic development of evidence-based practice.

A national action plan, or strategy, is needed to reduce the incidence of cerebral palsy and to support those living with this condition.

Cerebral palsy is a relatively common condition. In France, a high number of children and adults live in specialised residential care accommodation and yet there is no national strategy for cerebral palsy. To date, the French government has developed four successive national action plans for rare diseases, one for people with multiple and profound disabilities, and a national strategy for autism… but nothing for cerebral palsy. Children and adults with cerebral palsy instead must make do with whatever services happen to be available in their area. This response is totally inadequate; and it leads some people to despair.

Cerebral palsy symptoms are a unique combination of movement and postural disorders, often associated with disturbances of sensation, perception, cognition, communication and behaviour, and often including musculoskeletal complications and pain. It is a lifelong condition and yet care is offered by separate service providers based on age; and there is no-one to supervise the transitions

According to the International Classification of Functioning, Disability and Health, **a disability is the result of biological, personal and environmental factors**. **Why, then, is there no holistic overview for people with cerebral palsy when care goals are being agreed with the person, or with their parents if they are a child?**

The absence of a national strategy for cerebral palsy in France means there are no healthcare and social objectives for this population, no monitoring of results, and no funding! This means there is also no possibility for the community to progress. The failures, described so strongly, and emotionally, by the people interviewed for this White Paper, whether in the field of health, school, work or everyday life, cannot be allowed to continue.

The commitment and work of associations, scientific societies and the Fondation have made it possible to refer this matter to the French Health Authority so that they can issue recommendations for best practice relating to the rehabilitation of people with cerebral palsy.

Even as these recommendations are about to be published, however, we ask if there is an awareness of the considerable effort that will be necessary (in terms of training, service transformation and support provision) that will enable them to have the desired positive effects?

It is, therefore, time to talk and work together: people with lived experience of cerebral palsy, professionals and administrators. Stakeholders at a national level are ready for this but we also need to be open to international cooperation. There are 17 million people affected by cerebral palsy worldwide who could also benefit from this work.

Building an inclusive society means recognizing each person's individual needs and **making freedom a reality for them: their life should not be determined by their disability, but by their choices**. This freedom is not a given; it should instead be the result of collective efforts. This White Paper shows the path to follow.

Alain CHATELIN
Parent of a person with cerebral palsy
President of the Fondation Paralysie Cérébrale

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Chairman of the Scientific Council

WHITE PAPER: INTRODUCTION

The future for children and adults living with cerebral palsy is often bleak, and yet society continues to turn a blind eye. One new-born baby is affected every 6 hours in France: this figure is far too high and could be reduced since prevention is possible in some cases. The life of people with cerebral palsy typically follows a difficult path, paved with inadequate support and poor care provision from childhood to old age.

The current approach to supporting those with cerebral palsy and their families uses care plans from another age. The lack of solutions throughout life, and especially at key stages, results in wasted opportunities, and in people's needs and wishes being overlooked. To overcome this, we need a will that is equal to what is at stake: we have the right, our children have the right, like everyone else, to fulfilment and to a place among our fellow citizens.

Recognition of the United Nations' Convention on the Rights of Persons with Disabilities is necessary, but it is not enough. People involved with this issue oscillate between weariness and anger at seeing so many good intentions poorly converted into action, and so many stereotyped, or fragmented responses.

The answer lies in change. Nothing will be possible without:

- innovation in the analysis of the situation, making full use of the views of people living with cerebral palsy.
- innovation in the choice of co-ordinated, measurable and enforceable rehabilitation objectives.
- innovation through scientific research, conducting therapeutic trials into developing new technologies and new rehabilitation methods, into the prevention of brain injury, as well as finding new methods of education for children and young people with cerebral palsy.
- innovation in the dissemination of new thinking and approaches across regional boundaries and socioeconomic classes.

A national strategy for cerebral palsy would allow this paradigm shift and would provide a response to the anger. We, the Fondation Paralysie Cérébrale, and our partners, want to help: this document, based on the testimonies of people living with cerebral palsy and professionals in this field, is a start. This joint statement seeks to define what, in 21st century France, prevents people with cerebral palsy from participating fully in society, why society is not benefitting from the knowledge and strengths of those with cerebral palsy and, in particular, how support for those in lower socioeconomic classes who do not live in cities with easy access to healthcare can be improved. We have based our thinking on existing public strategies, **especially the 2018-2022 French national health strategy which had four main objectives:**

1. Implementation of a health promotion policy, including prevention, in all settings.
2. Combatting social and regional inequalities in access to health care.
3. Guarantees regarding the quality, safety and relevance of care at every stage of the healthcare process
4. Innovation to transform the health system by affirming the importance of service user inclusion.

The national health strategy also specified that these objectives required **"a coordinated and concerted inter-ministerial approach"** which supported development of "specific action strategies for certain areas".

So, we would like to use these foundations to help build a national health strategy for cerebral palsy. However, alone, this is insufficient as there are gaps in the statement of the national health strategy with regards to cerebral palsy. Namely:

- The national strategy only considers disabilities that are acquired during a person's lifetime, or those that change rapidly. **Cerebral palsy is present from birth and its symptoms are not fixed**, but the changes are not usually rapid, and it is neither degenerative nor particularly rare.
- The national strategy was developed by the French Ministry of Health (*Ministère des Solidarités et de la Santé*) without consultation, this meant that aspects which depended on other ministries have not been addressed, specifically:
    - The Ministry for Higher Education and Research (*Ministère de l'Enseignement supérieur et de la Recherche*), regarding the discovery of new treatments and preventative measures, as well as the dissemination of these findings.
    - The Ministry of National Education (*Ministère de l'Education nationale*) to enable social integration.
    - The Ministry of Labour (*Ministère du Travail, de l'Emploi et de l'Insertion*) to facilitate professional integration and reduce social exclusion.
    - The Ministry of Culture (*Ministère de la Culture*) to promote access to culture for all.

THE PREPARATION OF THIS WHITE PAPER

This White Paper was based on **a large national survey (ESPaCe survey)** of a thousand people living with, or caring for someone, with cerebral palsy. The results revealed overall dissatisfaction with care. Following on from the survey, **a rehabilitation charter ('*charte de la rééducation/réadaptation*')** was drawn up by the researchers, in conjunction with both cerebral palsy professionals and the participants, people who were living with cerebral palsy. It has since been signed by the French Secretary of State for People with Disabilities, major associations in the field of disability, relevant scientific societies and more than a thousand people.

We have devised a method to allow shared reflexion between individuals living with cerebral palsy and professionals in the field. Sixty people (parents of children with cerebral palsy, adults with cerebral palsy, and healthcare professionals) shared their opinions on the four main objectives of the national health strategy.

Each of the four objectives was separately discussed in a group of about a dozen people. The four workshops each lasted for about four hours, spread over two sessions. **The discussions were structured using recognised and validated qualitative methodology and were facilitated by three trained professionals**. Before each workshop, participants received information about the project and completed a questionnaire. Afterwards, participants worked together to jointly create a text that laid out priorities for action, and proposed solutions.

The aim of the work was not to exhaustively list the countless difficulties encountered, but rather **to establish a list of priority topics that could be practically acted upon**.

A steering committee then drafted an overall synopsis that addressed the key topics identified as most important by each workshop one-by-one. The process was repeated, and the subjects discussed were collated. This resulted in some repetitions, which were deliberately left in the text. An independent review committee helped with the final edited list.

This White Paper, therefore, is a synthesis of the results from these four workshops. Discussion summaries were agreed upon by the participants. It forms an introduction to the work that is needed to create a national strategy that is truly for cerebral palsy.

SUBJECT 1

Centres of Cerebral Palsy Care Excellence

THE FINDINGS

Difficulties in finding the right people and therapists, knowing who can help you, where to discuss your needs, and how to learn about care options were issues that arose frequently during the workshop discussions. Many different words were used for sources of advice, such as reference centres, resources personnel, multidisciplinary consultations, health education, peer discussion, peer helpers, family helpers, mobile team, and hospital-community links. The topic of how to access the best information was mentioned so often that it clearly indicated that it was a key need.

The type of guidance sought covered a range of areas, including:

- age-appropriate health advice for people with cerebral palsy.
- Information on rehabilitation and 'alternative' treatments.
- advice about school choices and career guidance.
- information about normally private matters, such as emotions, intimacy or sexual matters.

The results showed that the need for advice was raised most often by adolescents and young adults, and then by people at the first signs of ageing. The results also indicated that their current sources of such information, such as family doctors, paediatricians, private therapists, school careers advisors, or family members, were inadequate, unable to deal with the complex situations encountered by people with cerebral palsy.

Attempts to address this issue has been made by the French health service. A network of residential care facilities throughout France for people with disabilities was created in 2005 called the MDPH, (in French: *Maisons Départementales des Personnes Handicapées*). Furthermore, legislation passed in 2017 required each of the *départements*, which divide the country into local government regions, to organise dedicated consultations for individuals with complex situations or disabilities. However, it is clear from our results that these consultations are not working and that the MDPHs are also failing to provide the information that people with cerebral palsy seek.

In addition to residential care,

community care structures also exist. For early childhood there is the CAMSP network of centres (in French: *Centre d'Action Médico-Sociale Précoce*), and for the provision of specialist home-based care services there is also the SESSAD (in French: *Service d'éducation spécialisée et de soins à domicile*). Although these interventions can be effective, they often have long waiting lists and access is very slow. In addition, the handover between services (once the child is older than 6) can be difficult. It should also be noted that these establishments were not highly considered by participants in terms of quality, and were criticised for providing poor care programmes, especially rehabilitation programs.

> *"If you are not able to do your own research, to fill in the forms for yourself, you may miss out on your rights."*

The discussions with service users provided a better understanding of their expectations and, in turn, the reasons for previous health service failures. One participant summed this up by saying: "*Standards not standardised!*"

Any generalised solution, aimed at "*a (stereotyped) person with cerebral palsy*" and that used the words "*a reference system for people with cerebral palsy*" can, it seems, only lead to more disappointment. What participants reported wanting instead were opportunities for meaningful exchanges: for decisions to be made by themselves (as the person with cerebral palsy and/or their families) in agreement with the professionals involved in each aspect of their care and life. This included not only medical specialities such as physical care and rehabilitation, and general health, but also educational and careers guidance, and aspects of daily living.

Participants said that they wanted to avoid "*working in silos*", meaning that they wanted their care plan to be integrated into their environment, so that the role of the environment in their disability would be considered. This is something that is also supported by the 2001 ICF report (International Classification of Functioning, Disability and Health - ICF).

Valuing the point of view and knowledge of the person with cerebral palsy is essential; they know when they are talking to someone who lacks knowledge about cerebral palsy or does not show consideration for them (due to speaking difficulties, for example). Discussions should take place in centres of excellence, within flexible groups or networks, and they should involve informed personnel, such as peer helpers or other assistants, who actually know what resources are available.

> *"Parents should not be the coordinators of their child's treatment."*

The keywords for new solutions are, therefore, dialogue (and not explanation), privacy (and not intrusion) and participation (and not defining service users' needs for them).

The diversity of needs both among people with cerebral palsy, and at the different stages of their life, requires a multi-disciplinary approach to ensure coordinated, appropriate care. Such planning needs an underlying expertise in cerebral palsy that recognises the wide range of different motor and intellectual disabilities that characterise the condition, how they vary in severity, and how they change over time. In addition, care organisers should recognise how access to this information is determined by environmental factors, such as socioeconomic background and regional variations. Ignoring this complexity or choosing to start by planning care for only the simpler periods of life (e.g., early childhood) and then not to go any further, would mean that the response would not be fit for purpose, and would lead to fresh disappointments.

PROPOSED SOLUTIONS FOR DEVELOPING A NATIONAL STRATEGY

1. **Create regional centres of cerebral palsy excellence**. In France there should be one in each of the 101 *départements*. The terms of reference for these centres are essential for future discussion:

The organisation of the centres should prioritise the needs of adolescents, adults and the transitions between life stages.

- Each centre must provide a central point of reference for all rehabilitation planning for people with cerebral palsy in that region. This will enable care professionals and service users to discuss together the various rehabilitation or physiotherapy techniques and to establish personalised, and measurable, goals. In France, where rehabilitation services are offered by independent practitioners (rather than as an in-house service within a hospital or GP surgery) the centre would act as the point of contact for these independent care practitioners.
- The centre should provide continuous professional development training for therapists on new rehabilitation methods.
- The centre should provide people with cerebral palsy with access to allied healthcare services such as general medicine and dental care

as well as specialist care, especially gynaecology, urology, and cancer screening. These may be either in-house consultations, or external appointments, organised within a network of practitioners who are all trained in the specificities of cerebral palsy.

2. **Help during early childhood must continue to be based on existing structures** (SESSAD and CAMSP). However, access to them is sometimes difficult, often with excessive delays in getting an appointment; a difficulty that is reinforced by socioeconomic and regional inequalities.
Disruptions in care continuity often occur at the start of primary school and at the end of childhood. These periods should be anticipated and planned for by a dedicated contact at the local centre of excellence. The sharing of medical records should also be facilitated.

> *"Stop believing that 'everything stops' at adulthood."*

3. **Support for people with severe disabilities should be organised around existing structures** but there must be links with the referring centres, particularly for the establishment of annual rehabilitation objectives, specialist consultations, and the search for solutions for people who have had a breakdown in their care.

> *"Professionals do not talk to each other and do not listen to parents and patients."*

4. **The role of MDPHs needs to be completely rethought**. There are multiple problems with the current situation: difficulties at the point of entry; a lack of flexibility in the help offered; issues identifying people who are receiving inadequate care; and slow administrative decisions.

> *"We were lucky to find a trained physiotherapist."*
> *Should it be a matter of luck?*

1 child

EVERY

6 hours

WILL DEVELOP CEREBRAL PALSY

IN ONE REGIONAL ASSOCIATION (ODYNEO):

35 **CHILDREN**
are on a waiting list for a CAMSP
(90 places available)

46 **CHILDREN**
are on a waiting list for SESSAD help
(68 places available)

ONLY
30%*
of people receive
SPEECH THERAPY

*ESPaCe survey 2018

yet
60%
of people reported having
DIFFICULTY WITH SPEECH

1/2* people
INTERVIEWED
reported **difficulties finding a physiotherapist** trained to treat cerebral palsy

1/3* people
INTERVIEWED
experienced **interruptions** in their **physical therapy** at some point

* ESPaCe survey 2018

OBSOLETE?

OPINION NO. 118 OF THE NATIONAL CONSULTATIVE ETHICS COMMITTEE (SEPTEMBER 27, 2012)

IN TERMS OF THE **SEXUALITY OF DISABLED PEOPLE,** THE CCNE DOES NOT RECOGNISE ANY DUTY OR OBLIGATION ON THE PART OF EITHER THE COMMUNITY OR INDIVIDUALS, **EXCEPT IN THE FACILITATION OF MEETINGS AND A SOCIAL LIFE** (...). IT SEEMS THAT THE FACT **SEXUAL ASSISTANCE SHOULD BE AN ENTITLEMENT PROVIDED BY THE STATE**, AND THAT IT DEPENDS ON NON-INDIVIDUAL INITIATIVES, IS DIFFICULT TO ACKNOWLEDGE.

WHAT IS THE ANSWER?

The ambiguous status for sexual surrogate partners (known as "aidants sexuels" or 'sexual assistants' in French) should be resolved. There is a demand for legislation to change and for the training and supervision of professionals to become possible. The use of surrogate partners from neighbouring countries should no longer remain the only option.

5. **The whole education system: schools, colleges, apprenticeship schemes and universities all need to work together creatively to link** families and teachers or educational advisors, to share information about cerebral palsy, general advice and any information that will facilitate the students' learning, while respecting their confidentiality. Important gaps in support appear when students are thinking about career choices at school and accessing their first job. In both cases, the increased level of support required by these students should be anticipated because multiple opinions will need to be considered.

Students should also be helped to understand what support is available to them so they can communicate their needs as they move between placements. They should be included in the discussion as soon as possible when their schooling and career plans are discussed.

> *"Inconsistency in access to reimbursed care (such as psychomotor or occupational therapy) and disparity in the refunding of care between different residential care facilities (MDPHs)".*

6. **The need for improved guidance and support for people with cerebral palsy so that they can be emotionally satisfied and able to have intimacy and sexual relations.** The opportunity for intimacy is hampered by multiple factors including reduced accessibility to social venues, physical dependence on another person, a loss of personal privacy, and issues surrounding acceptance of both oneself and others. Exchanges with peers, information on contraception, and support during the discovery of their changing body must be organised. These discussion groups cannot exist solely in an electronic form, as this will exclude those with reduced access to the necessary technology.

Small group, or individual, discussions with a trained professional should be organised within each regional centre. In France, regulations on the possibility of sexual surrogate partners, which are allowed in some countries, need to be changed; the National Ethics Committee on Life Sciences and Health should review its opinion on this matter that was published 2012.

SUBJECT 2

Who decides on the quality and relevance of care?

THE FINDINGS

One axis of the national health strategy is entitled "Guaranteeing the quality, safety and relevance of care."
It seems an obvious title; who would want inappropriate or low-quality care? However: who establishes this quality, safety and relevance of care? What are the evaluation criteria? These are important questions throughout medicine, but the exchanges on this subject between people living with cerebral palsy and healthcare professionals were intense.

One reason for the intensity was that in French, the expression used, '*prise en charge*', translates into both 'providing care' and 'alleviating burden'. Thus, when participants were asked about their opinion on cerebral palsy '*prise en charge*', it created ambiguity and led to difficult discussions. Even the word 'care' was contested: healthcare professionals interpreted '*prise en charge*' as referring to care, something that lightened the load. For people living with cerebral palsy, however, the term referred to a 'burden' and the 'burden of care', especially how this responsibility falls, for the most part, onto them. 'Consideration' may be a better description: who considers what treatment is best?

"There is a gap between parents/patients and clinicians."; "There is a certain lack of understanding between parents and carers."; "It seems impossible today to reconcile scientific points of view and the experiences of individual families." "There should be a legitimate, neutral referee who the doctor and the family can trust."
Quotations from the workshop participants, revealed the depth of the difficulties faced and the need to investigate this situation further, if a satisfactory solution is to be found.

> *"I have 30 years of rehabilitation behind me, and nobody helps me to deal with care fatigue, discouragement, guilt…"*

People living with cerebral palsy report that a top priority for them is to have care which is relevant to their lifestyle. Only rehabilitation objectives that make sense to them appear relevant. Defining what makes sense means establishing measurable objectives that are common to the person concerned (or, if they are a child, their families) as well as to all the professionals involved in the rehabilitation. This approach must go beyond a simple dialogue, especially since the person living with cerebral palsy has often developed a greater necessary know-how about their needs. They have developed skills and tools that they find beneficial.

To see their valuable, practical knowledge denied by professionals is both incomprehensible and shocking. When making care decisions, it is crucial to listen to what the person wants, to recognise their legitimacy and to take their wishes into account.

The burden of a standardised, established rehabilitation care routine can be difficult to bear. Here, 'routine' refers to the rhythm of therapy: the duration of sessions and the techniques used. In France, the routine is typically composed of two, 20-minute physiotherapy sessions per week that are effectively offered for free (they are reimbursed by the French state). This standard offering ignores the complexities that characterise cerebral palsy in favour of a one-size-fits-all solution that cannot cater for individuals' specific needs. The dissatisfaction that naturally arises with the relevance or quality of such standard treatments leads to demands for access to a choice, and for people to be able to choose "*alternative treatments or care*" that could be reimbursed instead.

> *"My only pleasure is walking, and it keeps me in better health, but it is only possible when someone accompanies me."*

Nevertheless, **discussions also recognised the need for evidence-based validation of different rehabilitation therapies**. Such a scientific approach would not only identify new possibilities, but also reduce the risk of people getting swept away by simplistic or 'quick-fix' solutions that overlook the complexity of cerebral palsy.
It was noted that such evidence is lacking for cerebral palsy therapies, especially for adults.
This also highlights the need to increase the number of people with cerebral palsy and families who can participate as partners to enrich the training of healthcare professionals, as well as helping to support others with cerebral palsy, or new parents.

> *"In CAMSPs, care is almost exclusively social and educational, it is disconnected from physical needs."*

The challenge, therefore, is to find a way to reconcile and effectively combine the benefits of:

- professional experience
- methods and tools developed by people with cerebral palsy, either discovered for themselves or learnt from peers.
- a formal scientific evaluation and validation process for therapies, such as that proposed by the French National Authority for Health (HAS)

In our opinion, the quality, safety and relevance of care can only be established through dialogue, maybe even consensus, between all involved parties: doctors, rehabilitation specialists, people living with cerebral palsy and patient-partners. The evaluation criteria for the therapies offered must reconcile scientific evaluation and the consideration of the objectives of the person concerned so that the care plan proposed is both effective and truly individualised.

PROPOSED SOLUTIONS FOR DEVELOPING A NATIONAL STRATEGY

1. Tackling poor care coordination

The regional centres of excellence, as already described, would undoubtably provide a large part of the answer. They would provide a place for diagnosis by specialised paediatricians, a place for support and dialogue about cerebral palsy as well as a resource library for knowledge regarding therapeutic approaches and evidence-based practice.

To achieve these aims, the centres must have the following:

- Named key workers: Each person with cerebral palsy should have (easy) access to a named contact. Key workers should be based in the centres and their role would be to track, record and follow the care pathway of each of their allocated individuals from the very first entry into the system e.g., during diagnosis and through each life stage. Key workers will also offer expert advice to families, consult with service users, and provide support and guidance before decisions or specialist consultations. The repeated exchanges will provide a valuable insight into and record of the life project of each person with cerebral palsy in that region: the tools they have put in place and their objectives. While each key worker will be a touchstone for the person with cerebral palsy, their qualifications may differ (e.g., nurse specialist, or a peer helper or 'buddy', someone with CP who is specifically available to advise and support others) between centres or individuals.

- An up-to-date expertise and knowledge base. The centres should be able to provide evidence-based information on all rehabilitation methods, whether they are described as 'classic' or 'alternative'. This must be available to anyone who requests it, including not only people with cerebral palsy and their families, but also regulatory authorities establishing clinical guidelines or social security reimbursement agreements.

2. **Reconciliation of professional and individual-acquired experience.**

Bridging the gap described by respondents between individuals with cerebral palsy and clinicians requires that the decision-making processes within the referral centres focuses on:

- Helping individuals to make "specific, measurable, attainable, achievable, and time-defined" goals for all types of rehabilitation.
- How best to achieve the rehabilitation goals. This includes factors like which therapy, how often, and how intense should the sessions be.

Decisions should only be made following discussion between the person concerned, or their families, and their key worker, who will help to co-ordinate the different interventions such as physiotherapy, speech therapy, surgery, or medication, and the rehabilitation professionals themselves. The use of helpers, both for people with cerebral palsy (peer buddies) and parents of young children with cerebral palsy (parent buddies) should become standard practice. They will help to ensure that therapy choices remain consistent with the wishes of the individual with cerebral palsy and consider both their existing skills and new ones.

The opportunity for people to share experiences (peer-to-peer) either online or in person will help to share exchange knowledge about the scientific validity of different techniques and research activities.

ESpaCe Survey

ONLY 27% of subjects said that they were COMPLETLY **SATISFIED with their rehabilitation.**

SUBJECT 3

From school to work: adapting to individuality rather than rejecting complexity.

THE FINDINGS

For pupils and students living with cerebral palsy in France today, school is rarely either as liberating or inclusive as it should be. Efforts to facilitate accessibility and integration have been made, particularly at primary level, but countless barriers remain, especially when moving on to secondary, further and higher education, vocational training and work. The main criticism noted by participants was that there was a lack of flexibility throughout the educational and career system when it was faced with the unexpected particularities of cerebral palsy.

> *"Rehabilitation helped me to become aware of space, simple notions of up/down, front/back, top/bottom, which were difficult for me to understand."*

Institutions should adapt to the singularities of pupils with cerebral palsy. Unfortunately, there is currently a tendency to dismiss complex factors as being too individualistic. Parents and young people have become accustomed to delegating decisions about teaching to teachers, and about learning environments to the school. Nationwide educational programmes have been established and it is up to the teachers to make adaptations for the pupils in their class. This does not work for pupils and students with cerebral palsy, especially those who have intellectual as well as physical disabilities. When families and young people allow the school to make decisions on their behalf, even in the best-case scenarios, they still find themselves acting as an advisor to teaching staff, or as a messenger relaying information from one to another. At worst, these children and their families are ignored, and risk being side-lined or transferred to a 'specialised unit'.

This lack of support in accessing appropriate education led to complaints during the workshops about:

- **The lack of anticipation and fluidity between educational steps**; from starting primary school to, for those who can, progression through secondary, further, higher or vocational education. The task of orienting and preparing for these transitions must begin earlier for children with cerebral palsy.

- **The absence of cerebral palsy educational experts who can analyse the individual situation.** Staff in residential care facilities (the MDPHs) are not reported to be of any help in this area. Access to information about the complexity of cerebral palsy and ways to reduce its impact on the individual should be improved and made available to all schools. For some areas, such as the educational and intellectual aspects of cerebral palsy, more research is needed first as there is very little information currently available.
- **Access to adaptations and resources is not universal**. Suitable classrooms are sometimes only accessible by changing school, which must be balanced against the disruption to friendships and a social life. Even when a classroom is adapted, other rooms or resources in the school may still be inaccessible.
- **Students with cerebral palsy are often routinely 'excused' from certain activities at school.** Official exemptions from physical education, sport, outings, or other cultural activities are detrimental for pupils as both exercise and a wider, social experience is particularly important for young people with cerebral palsy.
- **All children in areas of social deprivation and on lower incomes** are far less likely to have a positive experience at school than those in wealthier, better resourced establishments. These socioeconomic and geographical inequalities are particularly marked for those with cerebral palsy.
- In France, **assistants for school children with disabilities are known as AESH (A*ccompagnants des Élèves en Situation de Handicap*).** They include AVS staff (*Auxiliaires de Vie Scolaire*) who work in schools to support the teachers as well as other professionals who provide educational support in the child's home. These AESH all need better recognition: staff need more support and a clearer role, their in-service training is insufficient, and increasing the pay would attract applicants with higher academic levels who could support students at higher levels of study. The support received by children is too fragmented, both on a weekly and annual basis, as well as between school and home.

> *"Valuing these support staff, paying them well (especially at school)."*

Further analysis of the complex factors that affect the education of people with cerebral palsy is needed. Nevertheless, certain facts already stand out:

- Intellectual impairments can be hidden, and difficult to explain by rehabilitation doctors, neuropsychologists, families or even the person themselves. Intellectual difficulties and special educational needs cannot be summed up in one convenient word; finding the best learning environment requires time, patience, co-operation, trial and error.
- Within the cerebral palsy community there is an ambivalence between a desire for 'normality', where all children are equally integrated within mainstream education, and the desire to have an individualised programme, especially at key points in the educational pathway.

> *"It is difficult, when you move from one town to another, to be turned away from physiotherapy practices because they find your treatment too complicated."*

The variation in disabilities that naturally occurs between students with cerebral palsy prevents the implementation of a one-size-fits-all cerebral palsy educational intervention. Some students with cerebral palsy study at university, live independently and pursue a career, whilst others may need an educational project centred on helping them to achieve autonomy in daily life.

PROPOSED SOLUTIONS FOR DEVELOPING A NATIONAL STRATEGY

To best support students with cerebral palsy, we therefore need to consider their age, their aspirations and the nature of their disabilities, particularly intellectual disabilities:

1. **School and university careers guidance should be prioritised.** The school should play the main role here, it cannot be delegated to residential care facilities, health or sociomedical structures. The problem should not be the complexity of cerebral palsy, but rather a joint analysis of these complex factors should be the solution.

Anticipation, multidisciplinarity and

flexibility are the key words in this search for answers. There is not one pre-established solution, no 'right' way to help. Educational counsellors need to be aware of the variety of individual situations, and links must be established between them and the local cerebral palsy centres of excellence. The role of school counsellors needs to be reviewed. The participation of families and students is essential in education and career guidance discussions, but they should not participate in different conversations simply so that they can then relay the information to other stakeholders!

Not only do the material and human resources necessary to provide the required variety of educational support need to be rethought, but this should be done without widening existing inequalities by implementing simplistic solutions. One example given in the workshops described how a student was using computer resources in class with the help of a specialist teaching assistant; but if the assistant was absent, the resources became inaccessible.

2. **The support provided to students to help them prepare for their first job interview(s) and to support them during their first employment also needs to be reviewed**. At present, there are not even established communication channels to easily enable discussions between sociomedical professionals and the business community.

However, these relationships are necessary to create secondments, internships, work experience opportunities, and to make other mutually beneficial connections.

Existing services that help people with disabilities to find and remain in employment need to be involved. In France, these services are known as the *Cap Emploi* and SAMETH (in French, *Services d'Aide au Maintien dans l'Emploi des Travailleurs Handicapés*). Such organisations already have valuable expertise in supporting applicants, helping them to highlight their skills, finding suitable roles, and in communicating about this subject to increase awareness. The aim would be to focus on skills and possibilities, rather than disabilities. Employers would be helped to know what adaptations would be necessary in each case, especially if there are 'invisible' intellectual difficulties. Companies and businesses identified by students with cerebral palsy should be involved at an early a stage to facilitate and support any adaptations.

3. **The care and support provided in childhood such as early years services** (CAMSP) or home care (SESSAD) was

reported as usually working well, although the care offered was rather standardised and routine. As mentioned previously, there could be long waiting lists and a feeling of abandonment when childhood services finished. Another issue identified was that an excessive provision of rehabilitation therapy (including that requested by parents) during childhood sometimes led to the child receiving 'too much care'. This then caused them to later reject some, or all, of the rehabilitation offered to them as adolescents.

4. **More educational research is needed into how to support the individual with significant intellectual disabilities**. For these children, inclusion in a mainstream educational establishment cannot generally be extended beyond the first few years of primary school. The aim, therefore, should be to improve interactions with the environment and support the development of autonomy, whether they are at a day or a residential school. Annual, measurable goals must be set between the family and the rehabilitation team. For this, it is therefore necessary that schools are also in contact with their regional centre of cerebral palsy excellence.

SPECIAL TEACHING ASSISTANT AND CARER RATES OF PAY IN FRANCE

Minimum wage in France (hourly rate)
10.25€ (before tax)

This work is often **part time**

A monthly take-home salary (after tax) of
600€
for **20.5** hours work per week

CANADA AND THE NETHERLANDS HAVE DEVELOPED CHILD-ADULT TRANSITION SERVICES THAT INCLUDE CARE, RE-EDUCATION/REHABILITATION AND PROFESSIONAL INTEGRATION FOR THOSE WITH DISABILITIES.

KINGSNORTH ET AL 2011. The LIFEspan model

SUBJECT 4

Socioeconomic and regional inequalities reinforce the difficulties faced by people with a disability

THE FINDINGS

Living with cerebral palsy creates challenges that are not faced by those without cerebral palsy. Should socioeconomic and regional inequalities add to these issues, making life and its key stages more difficult than is otherwise necessary? It is easier to find solutions that are not simplistic or basic for those who belong to richer and more privileged socioeconomic classes; those who have broad access to information and who live in large urban centres where local solutions are more likely to exist. Even in terms of prevention, especially reducing the incidence of prematurity, factors linked to socioeconomic deprivation need to be addressed.

> *"I was not warned about this risk of prematurity even when I left the neonatal unit."*

We have found that **information provided to people with cerebral palsy and their families in France is often lacking.** During contact with residential care facilities (the MDPH), the responses given are routine; no attempts are made to adjust the information based on the profile of the

IN CANADA

THE INVOLVEMENT OF PATIENTS AND FAMILIES AT ALL INDIVIDUAL, ORGANISATIONAL AND POLITICAL LEVELS OF HEALTH CARE IS CONSIDERED TO BE **A ROUTE TO CIVIC AND DEMOCRATIC DEVELOPMENT.**

A STUDY* IN 2016 OF

1402

PREGNANT EMPLOYEES :

21%

CLASSIFIED AS BEING **DEPRIVED**

4X more frequently

exposed to **PHYSICAL HAZARDS AT WORK**

($p<0.001$)

4X more likely to

have **A BABY BORN PREMATURELY**

*HENROTIN ET AL. OCCUPATIONAL MEDICINE 2016

person with cerebral palsy (or their family). Similarly, the information provided by healthcare professionals also appears to be incomplete, particularly regarding the full range of rehabilitation therapies available.
As a result, the burden of searching for, and sorting out, information often falls on the person with cerebral palsy, or their family. It is a highly inequitable approach as it requires considerable time, effort, money, a certain educational level or other necessary experience.

In France, **access to equipment, techniques or specific care** (such as neuropsychologists, occupational or psychomotor therapists) is limited. It can be difficult to find these professionals outside of major healthcare centres in major cities, and there are often high out-of-pocket expenses associated with consulting neuropsychologists, occupational or psychomotor therapists, especially if they are in private practice, and so not reimbursed by the state. One example of a cost barrier was given in the workshops: a small child received a very heavy adapted wheelchair since it was paid for by the state, rather than a lighter, more suitable model, which was expensive, but would not have been fully reimbursed.

> *"For a person with a disability living in a rural area, it is more complicated to access some of the specialised facilities which are available in urban areas."*

Regional inequalities lead to feelings of resignation and injustice. Access to rehabilitation or specialised care is complicated, or even prevented, when it is not local. In some rural areas, for example, access to early childhood services (CAMSP) and or home care help (SESSAD) is also a problem.
In addition, making time-consuming, multiple, long, and expensive journeys, such as for twice-weekly physiotherapy sessions, creates unnecessary administrative and organisational burdens on the person and their family, especially if they do not have a car and there is a lack of local public transport services.

> *" Two children with cerebral palsy, each with mainly physical disabilities: one lived in département 93, the other in Levallois*. The first child did not have access to the exceptional school in the 17th [Parisian arrondissement], while the second one did. Their cases were identical on paper [yet] the one coming from the nicer suburb had far better 'luck' ".*

** Seine-Saint-Denis, also known as département number 93, and Levallois, are two Parisian suburbs known for being amongst the poorest and richest neighbourhoods in France*

Access to financial aid. At present, the benefits system in France is complex, and can be inflexible at key moments. Examples given were the impossibility of organising a personalised care pathway for a young child involving both CAMSP and private practice, the difficulty in transferring benefits at the end of the childhood period and then the complex revisions that had to be made depending on the parents' work or even marital status; the financial support available when the disability or fatigue made full-time work impossible.

> *"I'm 29 years old, I have an unstable gait and some speech problems, and I work three days a week as a cashier; I can't work full-time because I get too tired. When I am feeling well, I also teach some courses. I know that I will have to retire at a younger age than others. How much will I get?"*

.

Non-financial support is almost absent: carer breaks for families, help with travel, access to physical, sports and cultural activities.

There are wide socioeconomic, including regional, inequalities in the prevention and diagnosis of cerebral palsy. Inequality is particularly notable in the prevention of prematurity, which is the cause of 40-60% of cerebral palsy. Deprivation, known to be a factor that increases the risk of prematurity, must be addressed. This will involve not only improvements in antenatal monitoring, but also reducing the incidence of other, preventable risk factors such as smoking, obesity, poor diet and nutrition, occupational and environmental health risks, and the distances that need to be travelled to access care services. These inequalities also apply to children born at full term who are also at risk of, or subsequently diagnosed with, cerebral palsy although less is known about them as they receive less follow-up than premature babies.

PROPOSED SOLUTIONS FOR DEVELOPING A NATIONAL STRATEGY

1. **Greater interconnectivity and flexibility are required in the organisation of cerebral palsy care in France: the respective terms of reference of local health authorities (known as the ARS, or *agence régionale de santé*) and residential care facilities (MDPH) need to be rethought.** Regional centres of excellence need to be established to provide a local focal point. Each of the various players must have a well-defined

role, organised in a local network, in conjunction with patient and parent associations.
The priority for this organisation should be to extend care into areas away from large, urban centres, and to detect gaps in care, particularly for young people and adults.

2. **Provision of Information**. Comprehensive information must be available on rehabilitation methods and how to access these therapies. This should include details about 'alternative' methods, although the advice and content must be informed by the scientific evidence regarding each method. This information must be kept up to date. However, it is also essential to maintain the regular delivery of information orally via sessions in both the residential care facilities and the regional centre of excellence.

3. **Care and rehabilitation plans should be more flexible and responsive to the progress and needs of the individual.** For example, supporting intensive courses that run over several days, followed by 'rest' periods without therapy, could facilitate access to better rehabilitation. They are also easier for people with cerebral palsy to organise into their schedules and to access than isolated sessions lasting 20 minutes that occur intermittently over the week. Where appropriate, some specialities, such as occupational therapy, should also offer online consultations at a distance.

SUBJECT 5

Scientific research, evidence-based practice and progress for everyone.

THE FINDINGS

The participants in the each of the four working groups all **emphasised the need to increase knowledge about cerebral palsy, the need to "do research"** on all aspects of the condition.

Although the workshop discussions mainly focused on rehabilitation methods and techniques, other areas of research were highlighted. They included improving antenatal care to prevent known causes of cerebral palsy like prematurity, advances in adaptive equipment and other technologies, and the application of new neuropsychological findings to improve educational outcomes, especially for those with complex disabilities.

In addition to more research, the workshop participants also expressed a desire to see:

- Meaningful partnerships between the person with cerebral palsy (or their families) and researchers.
- Rapid translation of positive results from research to application in everyday life.
- dissemination of knowledge and continuous professional development for healthcare professionals in new methods and practices.
- Access to progress for everyone with cerebral palsy, especially adults, since "*the focus is currently on children.*"

It is necessary to *"...help as many people as possible benefit from new research and innovative practices."* and *"...reduce the gap between research and practice."*
Participants noted that, "*there is a lot of very promising research being done, but the reality on the ground is different.*" This means that *'there is a gap between what is presented at scientific conferences and the lived reality of parents on the ground"*.

In parallel with the demand for scientific progress and evidence-based validation of rehabilitation methods, the participants also considered individualised care plans to be a priority; sometimes this was described as a demand for "tailor-made"

treatment. This may seem contrary to the rigorous use of validated techniques, and this apparent contradiction must be further explored.

Such aspirations are not unique to cerebral palsy and are often expressed by those affected by other rare and under-researched conditions. **Nevertheless, they reflect a major change in the attitude of those living with cerebral palsy, at least in France: we found evidence of a strong demand for a rigorous scientific approach to rehabilitation before rehabilitation methods are applied for years** without further review, creating a burden on daily life and routines, and sometimes causing pain.

The validation of techniques by simple expert opinion, which has been common practice, must be replaced by higher levels of evidence. These consist of the results of formal therapeutic trials demonstrating the superiority of a new approach by comparing it to a control group who are receiving conventional care, as is now the case for all medical research. These trials would also facilitate the recording of undesirable side effects of rehabilitation, something that has been poorly evaluated in the past. The continued and persistent use of 'standard' and 'routine' techniques, that have not been scientifically evaluated, can no longer be tolerated. The same applies to methods that are sometimes strongly promoted but poorly defined and not evaluated (described by one participant as "*therapeutic drift*"). The 2022 publication of the recommendations of the French National Authority for Health on motor rehabilitation for people with cerebral palsy will help this paradigm shift.

In addition to wanting new research into cerebral palsy, adults and children (with their families) living with cerebral palsy also have several other, related demands:

- Scientific evaluation of current practices and so-called 'alternative' methods in addition to the evaluation of new techniques.
- For trials to be coordinated with their current rehabilitation, schooling programmes or life in general.
- To be involved in the definition of the endpoints of the study, reported benefits and undesirable side effects.

It is through partnership, a joint definition of goals and rapid implementation of changes that the demands for "individualised care" can be met.

PROPOSED SOLUTIONS FOR DEVELOPING A NATIONAL STRATEGY

1. **Increased funding and number of research projects on cerebral palsy; all areas should be included**: prevention, treatment, educational research, and technological research. A national network of reference centres, or even a European network, would facilitate the organisation and exchanges between such projects. Projects are needed for people with cerebral palsy of all ages, and not just for children, as is currently the case.

2. **Increase the partnership between researchers and adults or families of children with cerebral palsy.** People with cerebral palsy should be involved from the design of the trial, be part of the trial steering committee and then the monitoring committee. Their opinion should be paramount in defining the aims of the trial and the definition of adverse events.

3. **Focus on training:**

An effective partnership between people with cerebral palsy and researchers requires training:

- Training in research methods for those who wish to act as peer buddies and parent buddies. This training must be organised within the centres of excellence, in addition to the provision of regular information about international advances. These are the conditions for an effective partnership.
- Training updates for healthcare professionals on new and reviewed techniques and care organisation. Patients and parent-partners should be involved in this. For example, the Belgian HABIT-ILE (Hand and Arm Bimanual Intensive Training Including Lower Extremity) technique developed in 2011 has been clinically proven to improve functionality in children over the age of five. In France, the Fondation Paralysie Cérébrale are currently supporting a therapeutic trial to evaluate its effectiveness for younger children (aged from 1 to 5 years).

The main feature of this method is that it is based on an intensive course that, depending on the host centre, usually lasts for about ten full days and may be repeated annually. Replacing a re-education programme of weekly half-hour sessions that run regularly throughout the year with short intensive, immersive courses would require considerable reorganisation for care facilities, early childhood centres

(CAMSPs) and other therapy settings, in terms of their planning and schedules, staff expertise and ensuring the necessary equipment was available.

Videoconferencing and distance learning should be used to support face-to-face teaching for supporting families, those with cerebral palsy, and staff, especially as there is the advantage that online resources remain available for later review.

4. **In France, the methods of reimbursement and health insurance coverage should be more flexible.** There should be a possibility to rapidly set up trials when a new technique requires a different rhythm or approach, such as the intensive rehabilitation courses.

The **Fondation Paralysie Cérébrale** launched and is currently supporting a therapeutic trial on the **HABIT-ILE method** of intensive rehabilitation **IN 100 CHILDREN AGED FROM 1 TO 4 YEARS OF AGE.** The work is an international project coordinated in Brest, France.

In the USA, Australia and some European countries, developments in **rehabilitation technologies** (such as virtual reality) based on motor learning science (intensity, repetition, gradual complexity and motivation) are **being clinically validated.**

The Scientific Council of the Fondation Paralysie Cérébrale includes a family representative and a person with cerebral palsy.

Other people with cerebral palsy are invited to the final meeting about each project before the Foundation decides whether or not to support them financially.

CP-UP is a Swedish national programme of systematic **multidisciplinary follow-up** and **intervention protocols** for people with cerebral palsy. It has been shown to **reduce the frequency of secondary complications**. It has since been adopted throughout Scandinavia, but also in Scotland and parts of Australia.

Two evidence-based practice treatments for the prevention of cerebral palsy in women who are likely to deliver their babies prematurely have recently been adopted following therapeutic trials:

Prescription of **magnesium sulphate** for foetal neuroprotection in cases of imminent preterm delivery **before 32 weeks.**
(Published in 2018)

Prescription of **corticosteroids** for threatened preterm delivery before **34 weeks.**

The Fondation Paralysie Cérébrale is in the process of launching an international research call on the early diagnosis and screening of cerebral palsy.

Conclusion

The words in this white paper, shared by people living with cerebral palsy and professionals, indicate clearly that more is needed; too much suffering, weariness, and anger have been expressed.

At the moment, the care and support offered to those with cerebral palsy is too routine, and innovation is limited. Where we should be driving essential evidence-based practice forwards, scientific research activity has been reduced, support networks are fragmented, and access to them is inconsistent.

We conclude, therefore, that a national strategy is needed. This White Paper provides a medium-to-long term action plan to improve the prevention, support and care for people with cerebral palsy; action that can no longer be avoided or delayed. The work has already begun, and **people with cerebral palsy, families, carers, professionals and researchers are all ready to continue working together with the national authorities** so that progress can be made for future generations.

con-tributions

CONTRIBUTION 1
Paralysie Cérébrale
France

Paralysie Cérébrale France welcomes the quality of the work coordinated by the Fondation Paralysie Cérébrale and its partners to participate in the development of a truly national strategy for cerebral palsy.

This work, conducted in close collaboration with the people concerned, will make it possible to map the main priorities that, it is hoped, will lead to significant progress in the support of people with cerebral palsy at all stages of their lives.

Some of the proposals made are like those made by the wider community of disability associations, such as supporting home-living, improving the pay and conditions for support professionals, and changes in the regulatory framework for sexual surrogate partners. Other demands, however, are specifically linked to cerebral palsy, such as prevention, adaptation of the care system, training of professionals and support for rehabilitation research.

The proposal to create regional centres of excellence dedicated to cerebral palsy and, in particular motor disabilities, would certainly make it possible to provide concrete help and advice to people and these centres would also help to address regional inequalities that exist and which do not always make it possible to offer the same quality of support across the country.

At the same time, the aspirations of people with cerebral palsy are changing and it is important that society as a whole is prepared, and encouraged, to ensure that the conditions for a dignified, independent and fulfilling life are in place for them.

Our federation, and its entire network, have already embarked on a process of sustainable transformation of the support offer to meet the changing expectations and needs of everyone.

Paralysie Cérébrale France will naturally play its part in the achievement of the qualitative and quantitative objectives which have been identified by this White Paper.

In conclusion, we would like to express our warmest thanks to all the contributors who have resolutely committed themselves to this collective and constructive approach in the service of the cause of disability and cerebral palsy.

Jacky VAGNONI
President of Paralysie Cérébrale France

CONTRIBUTION 2

APF France-Handicap

APF France Handicap fully supports the publication of this White Paper on cerebral palsy and calls for it to be recognised by the public authorities in the form of a major national plan.

As a 'generalist' for motor disabilities and, more than ever, open to disabilities of all forms, APF France Handicap has always taken care to ensure that common struggles do not erase the recognition, and social or health considerations of specific associations: all equal - all different! CP is one of the most common causes of disability experienced by our members.

From our point of view, this White Paper represents a perfect synthesis of both common and shared proposals, starting with the first 'pillar' concerning the subject of carers and sexual surrogate partners, which is so important to our association. The specific proposals made for others underlines the individuality of each life or care plan in the broadest sense: being born or growing up with cerebral palsy, being a parent of a child developing with such a disorder, cannot be reduced to the issue of disability in general.

However, it is with a holistic approach to lived experiences that this White Paper calls for specific actions within the action plan framework. The only suitable political response should be the implementation of a national plan whose main lines have already been outlined by this rich and well-structured document: prevention, equal access to specialist expertise, full social participation, research, the details of rehabilitative or integrative care approaches, and, finally, where people themselves, and their families, will fit once everything has been put into place.

What has already been achieved for rare diseases or disabilities (such as centres of excellence and expertise, training, research, and support networks) must also be implemented for a condition such as cerebral palsy. This White Paper emphasises the overall frequency of this condition, as well as the considerable diversity of motor and associated disorders, which may include multiple disability, and their changing impact on the person throughout their lifetime.

In this respect, we may speak of the CP spectrum, in the same way as the autism spectrum was once discussed. The individuality and complexity have been recognised through successive national 'plans', all of which profoundly modified the social and medical perception and most importantly above all, the actual support and care of the people concerned, and their families.

APF France handicap hopes that this White Paper will be the starting point for political action of the same scope for people affected or concerned by cerebral palsy.

Pascale RIBES
President of APF France-Handicap

CONTRIBUTION 3

Collectif Handicaps

The Collectif Handicaps, a group of organisations of which the Fondation Paralysie Cérébrale in France is one of the 49 member associations, defends the shared idea that people with disabilities must be considered and be able to participate fully in society as individuals with rights.

However, while it is important for our society to pursue a coherent 'common law' regarding disability policy that recognises the rights of people with disabilities, this approach must necessarily be combined with individualised policies, i.e., each of which focuses on the aspirations and needs of one person.

Indeed, people with disabilities do not form a uniform group where everyone has the same expectations. The reality is more complex: each situation is different and requires a specific response that is adapted and tailored to the individual's daily life. This allows for unique responses to different situations which, as far as cerebral palsy is concerned, are still poorly known and, too often, stereotyped.

The White Paper on Cerebral Palsy is part of this necessary process of individualisation of rights, thanks to the collective and co-constructed reflection that included people who are themselves affected by cerebral palsy.

Many efforts must be made to enable effective participation in society. Accessibility to services, including digital services, information, equipment and public buildings is still, for all types of disability, far from achieved and more progress is needed to ensure that all people can participate as citizens.

The Collectif Handicaps agrees with the observation in this White Paper that public policies have not responded well to many of the demands made by people with disabilities over the years.

Although the road to an inclusive society is still long, the Collectif Handicaps supports initiatives such as the White Paper on Cerebral Palsy, which is a combination of both reflection and concrete proposals to respond to the double challenge of a generalised approach to cerebral palsy on the one hand, and an individualised approach on the other.

Arnaud de BROCA

President of Collectif handicaps

CONTRIBUTION 4

Société Française de Médecine Périnatale

Living with cerebral palsy (CP) is a daily challenge. The testimonies are unequivocal: the difficulties begin before the diagnosis and continue at each new stage of the person's life. The management of CP seems insufficient and is sometimes insufficiently coordinated in France; it is important that people are aware of this. Only a national action plan can allow an improvement in the quality of life of individuals with cerebral palsy. The Société Française de Médecine Périnatale supports the initiative of the Fondation Paralysie Cérébrale and the writing of this White Paper. This work has enabled the identification of areas for reflection that should allow real progress for the people concerned:

Changing perspectives

CP is often misunderstood by health professionals and the general public. We must recognise that, because of its various presentations, overall management must be adapted and is different to that for other disabilities. It seems to be essential to inform, and to change preconceived ideas.

Prevention

Medical monitoring of pregnancy, prevention of prematurity, and the implementation of neuroprotection protocols such as the ante-natal administration of magnesium sulphate are important areas of primary prevention. These efforts must be supported, especially for families who are socioeconomically deprived or who have poor access to healthcare. This is a priority for everyone who is involved in perinatal care: obstetricians, gynaecologists, sonographers, neonatologists, midwives, anaesthetists, child psychiatrists and psychologists.

Diagnosing

Families often describe the difficulty that professionals had in diagnosing CP. For at-risk new-borns, follow-up is most often set up to detect neurodevelopmental anomalies. However, it seems necessary to strengthen existing follow-up networks. Clinical diagnostic methods must be disseminated to early childhood professionals, and especially to paediatricians and general practitioners, to facilitate diagnoses for children who are not otherwise monitored within the networks.

Care

Early care is essential. The waiting lists for access to existing CAMSP-type structures are getting longer every year. It is not uncommon for the time taken to provide care after first contact to exceed one year. In 2021, rehabilitation should be individualised and adapted to the patient, their condition and their family.

Training - Innovation

Training of healthcare workers about CP is currently 'anecdotal'. Improving education for paediatricians must be a priority. It is also necessary to train and raise awareness in all of those who are involved in the patient care process (general practitioners, rehabilitation doctors, physiotherapists, psychologists, etc.). Research on CP must also be developed to create access to innovative strategies in terms of prevention, diagnosis and rehabilitation.

Restructuring

To support these initiatives, the creation of centres of excellence is necessary. These centres would be responsible for coordinating care, but also for innovation and research in this field. Epidemiologists should also be involved in order to improve evaluation and understanding of CP.

Prof. Michel Dreyfus
President of the SFMP

CONTRIBUTION 5

Société Française de Médecine Physique et de Réadaptation

Through this White Paper, the Fondation Paralysie Cérébrale has drawn a roadmap for the future with milestones that will improve the consideration shown towards people living with cerebral palsy. Seven priorities emerged from the workshops involving health professionals from various specialties, researchers, families and people living with cerebral palsy, of which several independently emphasised the need to improve scientifically established knowledge about cerebral palsy, to share this knowledge, and to disseminate it to professionals and families. Such a strategy assumes that there will be development of specific training, and the promotion of genuine rehabilitation sciences, as well as an ever-closer partnership between individuals with cerebral palsy and their families, researchers, and, of course, clinicians. There is also a need to support these people and their families throughout their lives, wherever they live, in what is specifically linked to cerebral palsy (rehabilitation care), but also in what is common to all individuals in terms of health (prevention, education, access to 'ordinary' healthcare such as primary care medicine, gynaecological care, or dental care), and in terms of fulfilling their life project.

The 7 founding pilars proposed in this paper naturally echo the approach that has been taken by SOFMER (Société Française de Médecine Physique et de Réadaptation) for several decades to promote excellent medical and paramedical research in the field of rehabilitation sciences, the dissemination of knowledge, the initial and ongoing training of health professionals, and the strong partnership with people with cerebral palsy and their relatives, to give them access to the care they need and to ensure their full consideration, which is the guarantee of a quality social inclusion. Physical and rehabilitation medicine (PRM), a holistic medical speciality of functional prognosis at all ages of life, will continue its commitment to accompany the Cerebral Palsy Foundation in the implementation of these concrete actions in a national strategy.

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Prof. Isabelle Laffont
President of SOFMER

CONTRIBUTION 6

Société Française de Neurologie Pédiatrique

The Société Française de Neurologie Pédiatrique (SFNP) is a learned society that brings together doctors who specialise in child and adolescent neurology. Its aim is to promote paediatric neurology in France by offering training, facilitating dialogue between professionals, and working with other learned societies and various institutions to support children and adolescents with neurological diseases.

Cerebral palsy is a common neurological condition that causes significant disability in children and which, unfortunately, persists into adulthood. Neuropediatricians are involved in the early detection, diagnosis and management of these patients. Early detection and correct diagnosis form the basis for management, but they only make sense if medical and rehabilitation care and comprehensive management are in place afterwards. Care plans must take all the dimensions of the person into account. This White Paper provides a realistic assessment of the challenges and the needs of these individuals.

While knowledge has progressed significantly in recent years, the gap between theoretical progress and the care offered in general has only increased. Moreover, access to care across France is highly variable. Each individual and each family should have access to the same quality of care, and it should consider the changing needs of the person with cerebral palsy over time.

The Société Française de Neurologie Pédiatrique is therefore joining forces with the Fondation Paralysie Cérébrale to contribute the development of a coherent national strategy for people with cerebral palsy, and their families, that will take into account all of their needs.

Prof. Stéphane Auvin
President of SFNP

CONTRIBUTION 7

Société Francophone d'Etudes
et de Recherche sur les Handicaps de l'Enfance

SFERHE, the Société Francophone d'Etudes et de Recherche sur les Handicaps de l'Enfance (www.sferhe.org), is a learned society that brings together medical and paramedical professionals who care for children with disabilities in France and in French-speaking countries. The society's missions are to share professional expertise in evidence-based practice, to promote research into the main causes of disability in children, and to fund research projects in the fields of care, support, education and prevention.

Cerebral palsy is the leading cause of motor disability in children and currently affects more than 125,000 children and adults in France. It is a lifelong condition that requires specialised follow-up and a dedicated medical approach via care teams 'on the field' as well as specialist teams of experts. We now have the rare disease plans, which have provided vital structure for care provision, research and teaching in this critical area by creating centres and networks throughout France.

On the ground, these exceptional developments have led to a gap that is difficult to tolerate. People with rare diseases benefit from highly coherent care and research/innovation at a national level, while children affected by the most common cause of motor disability in children worldwide, cerebral palsy, do not benefit from a national vision or support.

The main demand from individuals with cerebral palsy and their families is to have the medical and paramedical support necessary, as soon as possible, close to where they live, to enable children and adults to function as well as possible in terms of mobility, handling, learning, autonomy and, more broadly, in terms of participation in society. The response they need has less to do with genetics or medical treatments, and instead has more to do with (re-)education, (re-)adaptation and (re-) insertion into society: a speciality more commonly known as réadaptation in French, or 'rehabilitation' in English, as advocated by the WHO in their 2003 plan "REHAB 2030".

The field of rehabilitation involves many medical, rehabilitation and socio-educational professionals with specific training in this area. The current disparity of resources across the country is flagrant, and undoubtedly leads to lost opportunities for many people with cerebral palsy who have difficulty finding key professionals in this field.

We strongly support the State-level implementation of an ambitious French strategy for cerebral palsy, in which we, as professionals, will participate alongside individuals, families and associations. We, along with the Fondation Paralysie Cérébrale, also ask for the creation of regional centres of excellence and other national channels, to enable a thorough re-think on how to best integrate children with cerebral palsy in schools, for massive funding into the development of paediatric rehabilitation science research and a major increase in the number of specialist paediatric rehabilitation professionals in the country.

Thinking and acting for cerebral palsy on a national scale offers a double lever for transforming the system: on the one hand, developing a 'lifelong vision' of health services (prevention-birth-childhood-adult-ageing) and, on the other hand, decompartmentalising current services (hospital, medical and rehabilitation services, medico-social services, etc.)

Thinking and acting for cerebral palsy on a national scale offers two ways to transform the system: firstly, it will allow the development of a 'lifelong' vision of health services (prevention - birth - childhood - adulthood – ageing) and, secondly, it will allow a root-and-branch rethink into how care is currently offered (including hospital, medical and rehabilitation services and sociomedical services).

SFERHE is ready to support the necessary developments and transitions, not only for people with cerebral palsy and their families, but also for all children and adults with disabilities in France!

Prof. Sylvain Brochard
President of SFERHE

CONTRIBUTION 8

Institut Motricité Cérébrale - Formation et Documentation

The Institut Motricité Cérébrale, Formation et Documentation (https://www.institutmc.org), is a training organisation for health professionals in the field of cerebral palsy. It has been involved with the Fondation Paralysie Cérébrale for several years in several calls for action plans around cerebral palsy. We participated in the ESPaCe survey, and we have been a signatory of the Rehabilitation Charter since October 3rd, 2019. Through its training activities, the institute promotes and develops rehabilitation care quality and constructive exchanges between professionals, families or/and all concerned parties.

The Institut Motricité Cérébrale subscribes to, and supports the idea of, developing a national action plan for cerebral palsy, particularly in training for health professionals. Our thoughts on this are, as follows:

The basic training for physiotherapists in cerebral palsy and related pathologies is not fit for purpose. It is too often book-based and cursory. Only continuing professional development in this field is currently providing adequate training for rehabilitation therapists. 50% of people with cerebral palsy are treated by a physiotherapist in private practice.

There is a shortage of therapists (especially physiotherapists and speech therapists) employed in institutions due to a failure to retain and recruit these professions. Some establishments operate without an in-house physiotherapist and instead use contracted professionals who work on an ad hoc basis, which hinders the implementation of coordinated care when necessary.

The Institut Motricité Cérébrale is working with the Fondation Paralysie Cérébrale to develop a national action plan for cerebral palsy, in particular regarding training for health professionals. Efforts must be made on training in order to have:

Competent professionals who know how to act in any given situation. This is in line with point 3 of the National Health Strategy, guaranteeing the quality, safety and relevance of care.

Allowing private and general care professionals to access training and innovative teaching methods adapted to meet their needs and the demands of their patients: short, repeated training courses based on analysis of professional practice, regular coaching.

A re-evaluation of therapy professions through the implementation of a major national communication campaign aimed at care professionals in the field of cerebral palsy.

The Institut Motricité Cérébrale, alongside the Fondation Paralysie Cérébrale, will support developments in the training of healthcare professionals and improvements in the quality of life of people affected by cerebral palsy.

Dr Nejib Khouri
President of the IMC-FD

CONTRIBUTION 9

Canchild - Canada

Cerebral Palsy: A Modern View

This important White Paper offers details about a common child-onset life-long neurologically-based condition called Cerebral Palsy (CP). In reading this report it is essential that people understand several realities about CP – ideas that will help everyone to recognize the many ways that a 21st-century expansion of our thinking about 'health' can have a powerful impact on *what* we do, *how* we do it, and *why*. Briefly:

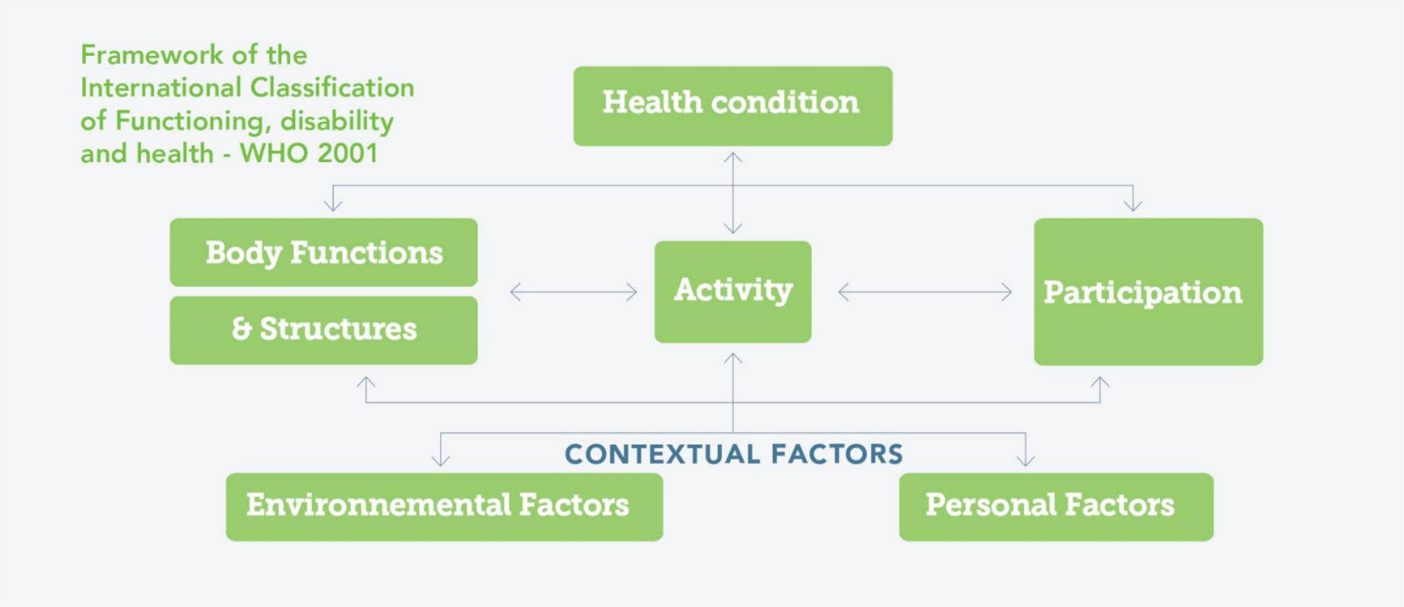
- The WHO's ideas about 'health' (2001) are captured in its ICF framework (ICF, WHO 20001 and ICF-CY 2008). WHO reminds us about the importance of 'functioning' (no matter how things are done); of 'participation' in life in ways that are meaningful to that person; of 'personal factors' unique to each individual; and of 'environmental factors' that impact everything we do.
- CP starts in very early life, and impacts children's – and families' – *development across their lives*. There are no cures – but many ways to offer services and be helpful.
- All our interventions must *build on strengths and personal factors*, focus on *promoting development of functioning, participation, child and family wellbeing* in ways that are important to them.
- CP is a *life-long condition*, with which people can grow, develop, function and achieve successes, even if they do things differently from 'normal'. Thus, we must *take a 'life-course' approach* to support children with CP and their families.
- There are many opportunities for *prevention* in CP:
    - **Primary prevention:** of prematurity, of maternal iodine deficiency, of ABO blood incompatibility. Many thousands of people do **not** have CP because we have identified and acted to intervene with these 'causal pathways'.
    - **Secondary prevention:** interventions and services for children and their families to promote functioning, parent and family wellbeing, and prevent secondary complications (including stresses and mental health challenges experienced by parents). We can do much more than surgery, therapies, and bracing.
    - **Tertiary prevention**: focus on the needs of people affected by CP, with the goal to improve quality of life by reducing disability, limiting or delaying complications, and restoring function. As always, this focus must include the family as well as the person with CP.

"Disability' is a social issue – outside the person with an impairment – related to environmental challenges (e.g., funding, access to community, resources, attitudes, opportunities, etc.).

Pr Peter Rosenbaum

MD, FRCP(C), DSc (HC), Professor of Paediatrics, McMaster University

Co-Founder of CanChild Centre for Childhood Disability Research



Framework of the International Classification of Functioning, disability and health - WHO 2001

CONTRIBUTION 10

Cerebral Palsy Follow-Up Programme, Sweden

It is striking how similar the needs and challenges are for adolescents and adults with cerebral palsy throughout Europe and elsewhere. In several countries pediatric and geriatric care includes multiprofessional teams, but for adolescents and adults with cerebral palsy the regular health care systems are usually fragmented and not well adapted for people with lifelong conditions. To improve the continuity of care throughout life, and bridge the gap between paediatric and adult care, Sweden initiated a multiprofessional health-care programme for adults with cerebral palsy (CPUP) in 2009. The transition from child- to adult services is flexible from 16 up to 19 years. Today, all health care regions offer ongoing follow-up within this programme to adolescents and adults. There are long term goals for the organizations both in terms of results (e.g. low prevalence of contractures) and processes (access to care, timely examinations). These are montiored in real time and information about how well the results actually meet the expectations are made publicly available online at our website.

Access to multiprofessional teams specialized in children and adults with childhood onset conditions should be the standard of care. Continuity of care is important through the lifecourse for people with more complex needs. Since1994, Swedish law has decreed that certain physically disabled people over the age of 20 years have the right to services by specialists and to rehabilitation in special units. These units are called Habilitation centres and are different from Rehabilitation centres. Rehabilitation focus on regaining abilities you once had and implies that after an injury and a certain period of time you will be fully or partially rehabilitated back to normal. However, people with childhood onset conditions such as cerebral palsy will need to develop new skills within all aspects of life from a very young age and continously throughout life. They are faced with different challenges in different phases of life such as pree-school, education, intimate relationships, employment, family formation and aging. They need to explore and find ways to navigate in life with their abilities. This could be challenging as they also face difficulties with fatigue, pain and a decline in function and abilities from an earlier age than others in their age.

This Livre Blanc sur la paralysie cérébrale en France is an important document that highlights some of the challenges faced by individuals with cerebral palsy and their families. Égalité is one of the core concepts in France and I sincerely hope this will guide future interventions and actions to increase equality, participation and social inclusion of all children and adults with cerebral palsy in France and set at good example for other countries to follow.

Elisabet Rodby-Bousquet
Physiotherapist and leader of the CPUP follow up program for adults with cerebral palsy
Associate professor in Orthopaedics, Lund University Sweden

CONTRIBUTION 11

Cerebral Palsy Alliance
Research Foundation, USA

As a first step in the development of a national action plan for cerebral palsy, this White Paper has clearly identified the main pillars of this strategy based on an accurate analysis of the current situation.

That said, a few remarks:

In the long run, scientific research will offer great possibilities to reduce (and perhaps one day, eliminate) the incidence of cerebral palsy and reduce the severity of associated disabilities (motor, sensory, and intellectual). It is, therefore, imperative that the national strategy for cerebral palsy includes the necessary resources for medical research. This medical research effort should also be coordinated internationally so that everyone can benefit from others' knowledge and collaborate on projects of common interest.

But it is also essential, as the White Paper points out, to ensure that these scientific advances are put into action in the national health system, both in terms of prematurity, and in terms of interventions and treatment techniques. Here again, exchange with other countries is important.

Ideally, a virtuous circle should be created that connects medical research for cerebral palsy, its application, and the needs of the cerebral palsy community: children and adults living with cerebral palsy, their families, and health professionals who specialise in cerebral palsy.

The other aspect that should be highlighted is that the success of a national action plan for cerebral palsy also requires awareness from the French people of what cerebral palsy is, and what is at stake for our society. To me, it seems essential to establish a communication and education campaign for the general public, that will also make it possible to generate the necessary support. And I would add that, in this context, we must create an inclusive society capable of adapting to the needs of people living with cerebral palsy.

The last point is that the psychological impact of cerebral palsy should not be overlooked, especially as children grow, during adolescence and throughout their lives. People with cerebral palsy can face a particularly difficult path in life, but their obvious disabilities (motor, sensory, or intellectual) are often less significant over the years in comparison to the psychological problems encountered by children and adults who want to be included, and to lead productive lives where their talents and skills are recognised, appreciated and developed in society (first in school and university, then in the world of work, and also in social relationships).

Jean- Louis Lelogeais
Chairman, Cerebral Palsy Alliance Research Foundation
Parent of a person with cerebral palsy

CONTRIBUTION 12

International Cerebral Palsy Society, Luxembourg

"One in two respondents reported difficulties in finding a physiotherapist trained to treat cerebral palsy." (ESPaCe 2018 survey, quoted in this White Paper)

Who would believe that in one of the richest countries in the world, half of the people with a particular medical condition would struggle to get the regular care they need?

It is not even a particularly rare condition; as this White Paper points out, a baby is born with cerebral palsy every six hours in France.

If this is the situation in France, can you imagine how difficult it is for people with cerebral palsy, and their families, to face the challenges posed by this condition in other parts of the world that do not have access to the same economic resources, social security or professional expertise?

I would like to thank the Cerebral Palsy Foundation for giving me the opportunity to share my thoughts on this White Paper. As the father of a fourteen-year-old child with cerebral palsy, it is the voices of the individual contributors quoted in the paper that resonate most strongly with me. They remind me of so many conversations, so many moments of frustration and despair, that we have experienced in our own family.

For this reason, I would also like to congratulate the Fondation Paralysie Cérébrale, its partners, and all of the individual contributors for taking these frustrations to task, for making sense of them, and for turning them into a thorough analysis of the needs of people with cerebral palsy, as well as of the systemic barriers that prevent these needs from being adequately addressed.

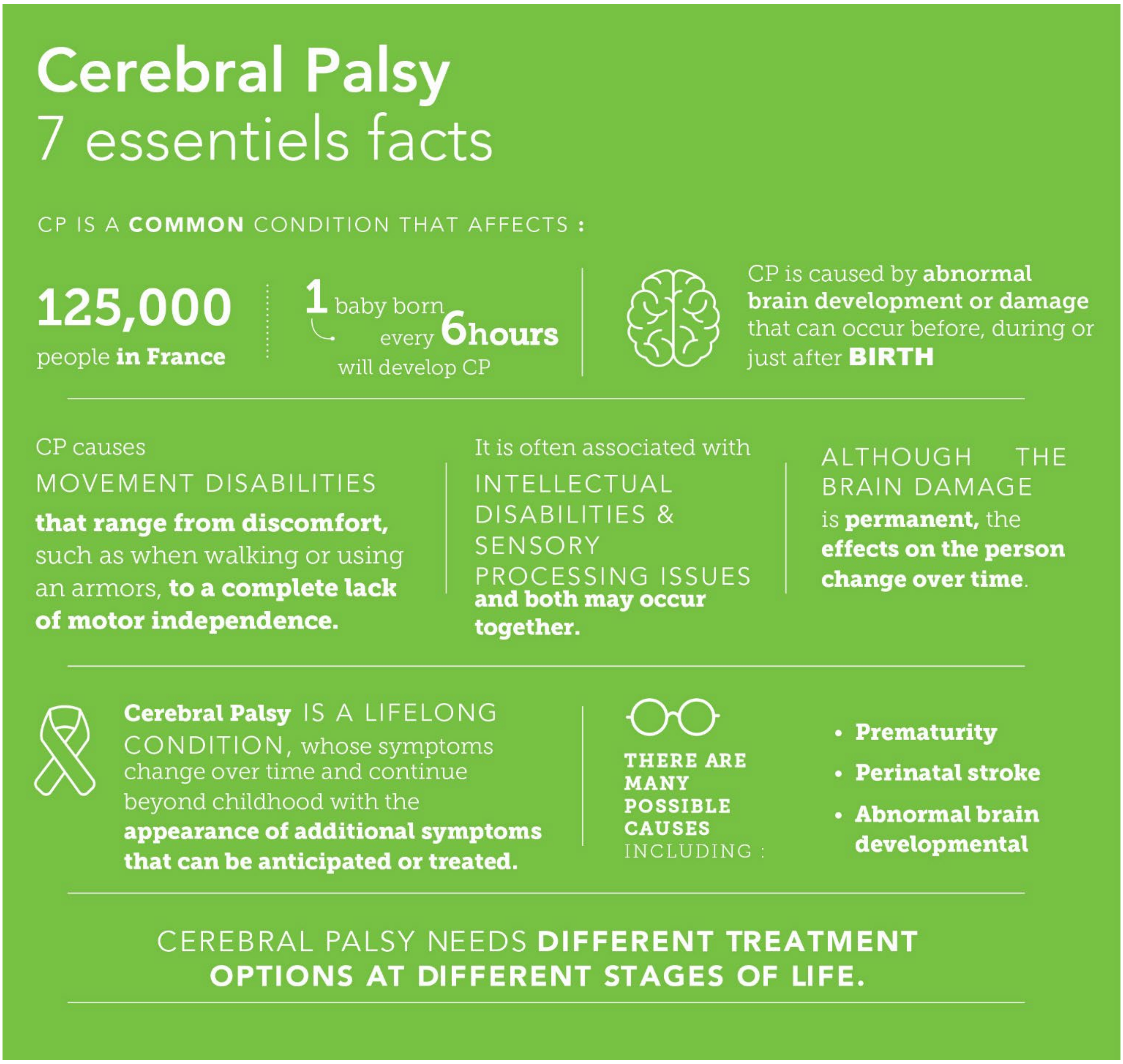
It is all the more remarkable that this document does not simply stop at describing the problems, but also puts forward a series of concrete proposals to improve the current situation. Many of these proposals will cost money, some will take many years to bear fruit, but they are all based on the lived experience of people with cerebral palsy - and thus they have a real chance of making a difference.

I would like to highlight one proposal in particular: "the creation of a Centre of Excellence in each *département*". There are many good reasons to combine the diverse professional resources needed to support those with cerebral palsy under one roof. It would ensure that everyone with cerebral palsy had access to the care they needed. It would make life easier for parents, who otherwise have to coordinate between and communicate with different private therapists and medical professionals. Equally important, however, is the benefit to be gained from the multidisciplinary collaboration itself: it allows doctors, therapists, other professionals and parents to work together in ongoing dialogue, to find the best solutions to the complex and individual challenges posed by cerebral palsy. Multidisciplinary collaboration improves care in itself and these 'Centres of Excellence' should be considered as a model for the treatment of cerebral palsy across the world.

There are inevitably some features of the situation described here that are unique to France, but the needs of people with cerebral palsy are the same all over the world, despite the differences between their countries. This White Paper can therefore serve as an example for other countries, both in the methodology used for its analysis, and in the content of its recommendations.

The White Paper is being launched on 6 October 2021, World Cerebral Palsy Day. This event serves to remind us that as many as 17 million people worldwide are affected by cerebral palsy. As part of its strategy to improve the situation of the 125,000 people with cerebral palsy in France, I encourage the French government, and civil society, to also not forget the millions of others who could benefit from their help, whether from shared results of pioneering research, the promotion of inclusion for people with disabilities in society through development aid, or through other acts of solidarity. As the World Cerebral Palsy Day slogan says, there are "millions of reasons" to improve the lives of people with cerebral palsy.

John Coughlan
Chairman, International Cerebral Palsy Society
Parent of a person with cerebral palsy



Cerebral Palsy
7 essentiels facts

CP IS A **COMMON** CONDITION THAT AFFECTS **:**

125,000
people **in France**

1 baby born every **6hours** will develop CP

CP is caused by **abnormal brain development or damage** that can occur before, during or just after **BIRTH**

CP causes MOVEMENT DISABILITIES **that range from discomfort,** such as when walking or using an armors, **to a complete lack of motor independence.**

It is often associated with INTELLECTUAL DISABILITIES & SENSORY PROCESSING ISSUES **and both may occur together.**

ALTHOUGH THE BRAIN DAMAGE is **permanent,** the **effects on the person change over time**.

Cerebral Palsy IS A LIFELONG CONDITION, whose symptoms change over time and continue beyond childhood with the **appearance of additional symptoms that can be anticipated or treated.**

THERE ARE MANY POSSIBLE CAUSES INCLUDING :

- **Prematurity**
- **Perinatal stroke**
- **Abnormal brain developmental**

CEREBRAL PALSY NEEDS **DIFFERENT TREATMENT OPTIONS AT DIFFERENT STAGES OF LIFE.**

WHAT IS CEREBRAL PALSY?

Cerebral palsy is a **complex motor impairment** that begins at birth and changes throughout life.
Brain injuries lead to motor, sensory (especially visual), cognitive and speech impairments which interact and evolve as the brain develops. Schooling, work life and rehabilitation all need to take the different motor deficiencies and associated disorders into account.

The rehabilitation needs of people with cerebral palsy are specific, therapy must offer an individualised, multidisciplinary approach adapted to each child and adult.
Prevention of cerebral palsy is possible; it is classed as either primary (avoiding brain damage) **or secondary** (minimising the consequences in the neonatal period). Prevention requires effective, multidisciplinary interaction involving obstetricians, neonatologists, paediatric neurologists, and physical medicine and rehabilitation physicians. Prevention strategies also involve the prevention of prematurity (a major cause of which has been established as socioeconomic deprivation and vulnerability) and innovations in neonatal care, including medical treatments.

THE GENERAL TERM 'REHABILITATION'

describes a range of interventions for :

- early rehabilitation (also called re-education),
- functional rehabilitation, and
- social rehabilitation (also known as reintegration) for children, adolescents and adults with a disability.

Rehabilitation is, therefore, a multidisciplinary response to improve social participation and the quality of life of people with disabilities. It must consider not only the personal characteristics of the individual, but also what role their environment and the representations of disability in wider society have played in the development of their disability.

[World Health Organisation (WHO) Report on Disability 2011.. URL: https://www.who.int/disabilities/world_report/2011/report.pdf
WHO Rehabilitation 2030: A Call for Action: https://www.who.int/disabilities/care/Rehab2030MeetingReport_plain_text_version.pdf)

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Innovate in order to transform our health system by reaffirming users' place

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On October 6, three young people are launching this appeal for a national action plan to the French government and other public authorities of the behalf of the 125,000 people in France who, like themselves, have cerebral palsy.

How can we move this appeal forwards? It is urgent.

This White Paper, a collaborative work, presents 7 pillars to underpin a national strategy.

This document is an English translation of
Part-1 Synthesis, Part-2 Expert contributions and Part-4 Participants,
of the "Livre blanc de la paralysie cérébrale" published in France on October 6th, 2021.
Part-3 Minutes of the Workshops is available in the French version of the paper at
www.fondationparalysiecerebrale.org