

# 15 years of research on Cerebral Palsy, part 2

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Research Letter

Since 2005, when the foundation was created with the ambition to expand research on Cerebral Palsy (CP) in France and in Europe, the understanding of its mechanisms as well as medical practice have made important progress. This 28<sup>th</sup> Research Letter, like the previous one published in November 2020, is dedicated to the evolution of knowledge made possible by these 15 years of research.

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### Warning:

This research letter was written on the basis of interviews that took place at the beginning of 2021. Many thanks to the distinguished researchers working on CP for their willingness to participate, and to Agathe and Pierre-Marie for sharing their experience.



## 1- A major issue: improving participation of people with CP



### Interview with Pr Bernard Dan

Neuropediatrician, ULB Université Libre de Bruxelles, Président of la Fondation Paralysie Cérébrale's scientific council

The definition of disability, or the handicap, determines the goals set for care. Pr Bernard Dan traces with us its evolution over time and the current stakes.

The perception and definition of disability changed a lot through the ages, so where do we stand today?

If we go back far in history, disability was once perceived as a stroke of fate, or even God's will. Then it appeared as a health problem, which seems obvious today.

But even this conception evolved significantly. When the World Health Organization (WHO) was created after the 2<sup>nd</sup> World War, we were still in a negative or default definition of health: it was defined as the absence of disease. The WHO changed this view by describing health in a positive way, as a state of physical, then mental and social well-being.

With regard to disability, the first approach was influenced by the medical model. We defined disability in regard to the limitations it caused: a problem of strength, of coordination etc, and we prescribed care or rehabilitation to solve these problems. This medical approach was of course useful and based on an ethical motivation towards the person we wanted to help.

In the 1970s, a new way of thinking disability emerged. We were still reasoning in terms of limitations, but the origin of disability was now attributed to society, not to the person. In what we call the social vision of disability, we consider that it is society that puts up barriers: it is stairs that create disability for persons in wheelchairs. So the issue became identifying these barriers: physical barriers but also certain attitudes towards the disabled people. This approach was adopted by countries such as the United States and the United Kingdom, on account of their wealth and of the organization of their health system.

Today we use the international classification of functioning, disability and health (ICF).

In 2001, the WHO proposed a new classification based on a multidimensional approach to the person (see the text box next column). This new approach even conducted to drop the word « handicap », like in English with the emergence of the notion of disability, or even « differently able ». In France and in Belgium we kept the term « handicap », even if we adopted this multidimensional approach to be able to continue to treat these persons.

The ICF is 20 years old and much remains to be done if we want to fully implement it. It provides a framework stressing what the person does and wants to do: the important is his or her participation in society, then we look at how we can organize the different dimensions to respond to their requests.

That said, this approach is not sufficiently known yet, and there are differences between countries, even between teams within the same country. Even if this approach is taught more and more, too often we still reason in an unidimensional way.

How does practice generally evolve?

The multidimensional approach to the ICF leads to multidisciplinary and interdisciplinarity: professionals must work together. That requires us to think about priorities in what we do and to re-focus on the person we treat. We don't « split » him or her, the project is unified and centered on what is meaningful for this person.

Taking into account the person's own goals (child or adult) makes a very big difference, which leads us all to humility. We used to expect practitioners to do their best, it was an obligation of means. But by setting a goal, we now address the notion of measurement: is the goal reached? And if not, should we refine it, make it more realistic, or adjust the means implemented?

What are the leads for the future?

We entered a new stage in care with the « family centered care » based on a partnership between the family and the team of professionals working with the patient, in particular in the decision making and the organization of care.

We also observed that the ICF lacks a dimension: the quality of life. The biopsychosocial model can be shared and considered objectively, but in contrast the quality of life is subjective. It is nevertheless an important dimension and optimizing it must be one of our targets.

It is clear that a child born today won't follow the same path as one born 20 years ago, who already had

a different life than the child born 20 years prior to that. The main reason for this is that children gained prominence: now they are listened to !

We also observed that the representation of disability is less caricatural than in the past, and the ICF is representative of this spirit, which is the spirit of our time, of a more inclusive society. The ICF doesn't say « normal » and « not normal », the norm is richer than before. The question of the meaning of life spread, we are opening to individual experience. To draw an analogy with sports, everyone can't be a champion, but everyone can thrive by participating.

To progress, we need to go beyond theory, to share stories of individual experiences: it will give more power to the persons concerned and to field practitioners.

## STATE OF HEALTH

Multidimensional definition and fictional example of a person with CP

- **Structure and functioning of the body:** brain injury, spasticity
- **Activities:** walking, writing...
- **Commitment in life and social participation:** autonomy of choice, education, leisure...
- **Personal factors:** motivation, character traits
- **Environmental factors:** housing, family, sociocultural context...

## My favorite words

Established in 2011 by P. Rosenbaum and J.W. Gorter, based on the ICF and on the work of CanChild, a Canadian research center dedicated to disabilities in children, these words describe the six notions that should guide care as well as the development of disabled children.

### My physical condition

**Structure and functioning of the body.** Everyone needs to remain in shape and in good health, including me. Help me find ways to keep in shape!

### My capacities

**Activities.** I may do things differently, but I CAN do it. How I do it is not important, so let me try.

### My friends

**Participation in society.** Having friends is important. Please give me the occasion to make friends of my age !

### My family

**Environmental factors.** My family knows me best and I trust them to do what is best for me. Speak with them, listen to them and respect them!

### My fun

**Personal factors.** When you're a child, having fun is important. That's how I learn and progress. Help me participate in activities that give me the most enjoyment.

### My future

One day I'll be a grown-up. Help me find ways to gain autonomy and to be a part of my community!

The « favourite words », originally created in English, were translated in many languages and adapted to



the cultures of different countries. More examples on <https://worldcpday.org/portfolio-item/the-6-favourite-words/>



## 2- Bring evidence to improve practice and better decide together



### Interview with Pr Sylvain Brochard

Pediatric Physical Medicine and Rehabilitation (PMR), Brest CHRU, Ildys Foundation, President of the SFERHE

Rehabilitation seems to be the natural support for the participation of disabled people. But to make practice change and to help families and professionals take the right decisions requires bringing evidence and validated practice recommendations, as Pr Sylvain Brochard explains.

You say that rehabilitation medicine changed a lot in 15 years, that we moved from a neuro-orthopedic approach to a person-centered one.

15-20 years ago, I received training which was quite centered on the issues themselves, the orthopedic deformities observed in children we were trying to solve. Today rehabilitation follows the general trend that is focusing on the person, their objectives, participation, and more generally their lives. It is a determining context element.

We now have new tools to make practice evolve. First, we have the results of studies, like the one on pain that we led, which was illuminating on how really live people with CP, or the ESPaCe study about their satisfaction towards rehabilitation (both supported by the foundation). We also learned to listen to

what « expert patients » tell us when sharing experience with professionals.

We also have support to implement partnerships with the people concerned, developed by the foundation or by other international organisms: the Rehabilitation Charter, signed with public authorities in 2019, which is a great tool to promote codetermination in rehabilitation programs between patients, families and professionals; the formulation of rehabilitation objectives considered « SMART », that is Specific, Measurable, Achievable, Realistic and anchored within a Time frame; and finally the « Favourite words » presented on the previous page, which are words that make sense to anyone and that we use increasingly to build individual projects.

[The concept of evidence also became central.](#)

Indeed, and it is an important change also following a general trend. Today therapeutic practices, including rehabilitation practices, must be based on scientific evidence, validated by studies: they cannot be based on peer experience and practice only, even if that remains important.

This culture was not very common in France, and we can thank the foundation for having progressively supported research programs that allow to build evidence at the European level, taking into account our specificities instead of being imported from the United States or Canada.

The next step is implementation, and in this respect we expect a lot from the publication of the High Authority for Health's recommendations, which should lead to big changes in practice.

[There have already been evolutions, like the emergence of intensive and playful therapies.](#)

These new therapies are based on the progress of knowledge in the field of cerebral plasticity. We have known for five to ten years that we need between 60 and 90 hours of intensive therapy to reach between three and five objectives. They are defined very precisely: « walk up the stairs to access such location » instead of « climb the stairs ». These methods are proven for children over the age of 6: the CAP' Study supported by the foundation now must determine if we can extend them to younger children.

To learn new motor capacities, we thus move towards short, intensive, playful methods, focusing on the function and personal objectives, rather than long-term neurodevelopmental therapies. Yet we shouldn't abandon other supports like in SESSAD that many countries admire: to help the child progress, we must manage to integrate short intensive sessions in his or her long-term program. We don't know how to do this yet and this paradigm shift is probably the next step.

Questions remain which are difficult to answer, encouraging modesty. In terms of neuro-orthopedics for instance, provision of evidence proves to be difficult. We are still operating on children who suffer from strong motor deficits, but we perform less interventions on small deformities as far as they don't block the function. But we lack evidence about the future of children we would have operated or not, and these studies seem difficult to lead for ethical as well as methodological reasons. We thus continue to build on our know-how, experience, favouring multidisciplinary decision-making with children and parents.

In a general way, we try to be the least invasive possible, and our objective is that the child spends the most possible time at school, in his or her family, and the least possible in rehabilitation centers.



[CP doesn't prevent from living and making projects](#)

What are the big challenges for the future ?

The first is the implementation of new practices based on research and the spreading of newfound knowledge.

Then we must continue research in rehabilitation. We need new evidence to be able to leave behind dogmas, thus helping families to get better information. Without validated studies that we can trust, how can they decide what is good for their child ? It is imperative to bring them evidence of effectiveness and security.

Finally, in line with the turn taken by research in rehabilitation, focusing on the person and the improvement of his or her participation, we now have to address the life-long aspects and the question of the future. Most of the persons with CP are adults, what do we do for them ? The foundation was one of the first to look into this topic, supporting since 2010 the Breton observatory for the child and adult care.

This French initiative spread on the international stage and is certainly a major stake for the future.

### TESTIMONY

Agathe, journalism student

I was educated in ordinary schools, with the help of an assistant in high school. The assistant provides logistical support, for moving from one place to another for instance, he or she also helps take notes. It is not perfect, the persons are not always trained, do not always know how to take notes, precisely, or are designated a few months after the beginning of the school year... Sometimes they also lack empathy, all that adds stress and I had a few difficult moments. My schooling was fluid, but it was a logistical challenge at the start of every year.

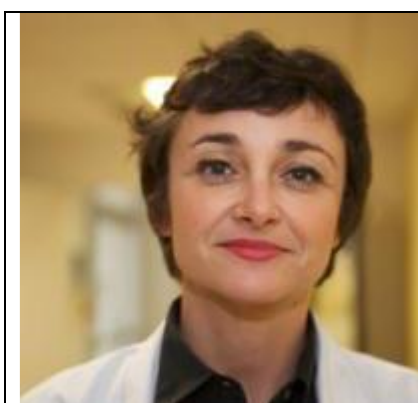
I benefited from the system of special education and in-home care, which makes on-site rehabilitation sessions possible, - I had them when the others had sports. At the university, the « disability mission » supports disabled students to implement the necessary accommodation, in particular the third period and the notetaker for exams and classes. The most complicated is to manage the unexpected as well as the daily life: rehabilitation + studies, sometimes it's heavy.

At the moment, alongside studying, I am working for an important national newspaper: I was given flexible hours, which allows me to plan rehabilitation sessions during the day and to avoid travelling at peak times. At work, my disability isn't a topic. It was properly taken into account by my employer at my arrival and now that I'm integrated, only my competencies are considered.

I always told myself that my disability shouldn't be an obstacle to my vocation. I asked myself if I should show a wheelchair on television, and when I happened to go on the air, I was once sitting on a coach, and once on my wheelchair. I got rather good feedback from my employer and viewers alike. Sometimes we put up barriers for ourselves because we have very few examples.

I have the life of a young woman my age: work, studies, social life. In fact, everything is a matter of organization. I work like any journalist of the staff, and on a daily basis you don't see the difference!

### 3- Addressing and evaluating pain better



#### **Interview with Dr Emmanuelle Chaleat-Valayer**

Physical and Rehabilitation Medicine, Centre des Massues  
French Red Cross, Lyon

Pain is part of daily life for people with CP, and represents one of their key concerns. It is however a relatively new research topic. An update from Dr Emmanuelle Chaleat-Valayer.

On the occasion of the prospective study led by La Fondation Paralysie Cérébrale in 2008, we uncovered the centrality of pain in the lives of people with CP. Is this topic better known today ?

A person with CP is very likely to experience pain, and that from the neonatal period: newborns in intensive care can undergo until 10 potentially painful acts per day. Over their life, pain will take two aspects: chronic pain in relation with deficiencies and their consequences (spasticity, joint deformity, etc), and care-induced pain (physio, equipment, injection of botulinum toxin, surgery...).

Research has done a lot these last few years to improve:

- the assessment of pain
- the management of pain in children with disabilities
- the management of treatment-induced pain through several validated recommendations

But much remains to be done, in particular in terms of training for health care providers, in regards to the affective and cognitive-behavioural aspects of pain (memorization, beliefs etc).

#### **What progress was made ?**

We are better at describing and evaluating how a person experiences pain. There was also progress in training and in recommendations for health professionals about analgesic protocols. There remains, however, the issue of training for the multidimensional aspects of pain.

The WHO describes pain as an unpleasant sensory and emotional experience associated with tissue damage. Pain is always the result of three « bricks »:

- nociception, usually understood immediately by all professionals and persons: any physical injury is likely to cause a painful stimulus,
- neurogenic pain, associated with altered nerve endings: pain is no longer visible, it is now a specific perception (sensation of burning, or of an electric shock). It can be detected with scales (DN4 for instance),
- and finally an emotional and cognitive-behavioural component: pain is an emotion, it is memorized, compared with older analgesic experiences, and will be the origin of behavioural reactions (complaint, run, prostration) that can lead to serious dysfunction of the central nervous system.

The novelty is that these dysfunctions were highlighted, as well as nociceptive pain, with functional MRI of the brain in several scientific studies.

Pain which is insufficiently addressed on these aspects during a first care session can lead to behavioural difficulties, an increased emotional perception in the following sessions, and can lead to an authentic care-induced post-traumatic stress.



It is thus imperative to evaluate pain, and for that to build on the subjective perception of the person, since there isn't a « pain thermometer » capable of including all its components. We thus use assessment scales (according to the age, the level of deficiencies etc), a device that is now satisfyingly codified in care services.

But new devices bring new perspectives: they use the analysis of the autonomic system tone, which controls the heart and the digestive system. The objective of these devices, in particular during general anaesthesia, is to provide non-invasive monitoring of pain and of the effects of the treatments. It is an effective control system of pain through monitoring of the parasympathetic activity, which gives information about the state of comfort or discomfort of the organism, and the emergence of a stress or pain. A « comfortable » patient will present dominant parasympathetic tone while an acute pain will activate the sympathetic system with mirrored decrease in the parasympathetic tone. This kind of tool is very promising for non-communicating or polyhandicapped persons, but not very widely spread yet. There are ongoing studies in the field of disability in France.

### What are the tools that caregivers can use?

Efficient analgesics, associated with nonmedicinal therapeutics like distraction or hypnosis, are part of the usual therapeutic tools. This association allows to memorize care in an adapted way.

More recently the importance of considering coping strategies was reported, covering all cognitive and behavioural processes used by a person to face a stressful situation, which exceeds his or her resources.

Pain is a real « stressor », at the origin of coping strategies that vary among the persons according to their beliefs, their propensity for anxiety, and also to environmental variables such as the nature of the painful situation, the social support, the emotional bond or the information regarding this situation.

Beliefs develop in everyone, progressively, according to personal experiences, to the chronic or repeated aspect of pain and its negative impact. They can also be culturally conveyed and turn out to be partially wrong (« feeling pain is the sign that you work well during physiotherapy sessions »). So they play an important role in the experience of pain.

« Coping » is a process, not a personal aptitude, and it evolves. The different strategies ensured to face pain were widely studied in said « typical » children. They are divided in two main categories.

Active or positive strategies are:

- distraction: I play a game, I play with my toy
- cognitive auto-instruction: I tell myself it's gonna be fine
- problem solving: I ask for medicine, I scratch the painful spot...

These active strategies help children handle pain more efficiently than passive strategies such as:

- catastrophism: I cry or I shout, I think it can only get worse
- helplessness: I think I can't do anything to reduce pain

Strategies evolve with age and older children tend to use cognitively more demanding strategies like the search for efficiency (strategies focused on the problem), which shows at the same time a better understanding of the painful phenomenon and increased autonomy in managing the situation. Several studies showed that the strategies ensured to handle pain played a major role in helping patients adjust to their pathologies, in terms of emotional distress, of disability and of life quality.

In CP, specifically, it was demonstrated in 2019 that children were using few coping strategies, thus seeming helpless, and that the evolution towards other strategies happened later in life, with use of cognitive auto-instruction in an isolated manner, stressing some sort of resignation.

So one of the objectives is to develop coping strategies, to reinforce them in care by fostering skills in children and families through a better understanding of care and by giving meaning to treatments, using objectives for instance. It also requires considering how the patients acknowledge or not their emotions, by giving them control in care delivery.

### We also see the emergence of new devices

The novelty in this arsenal is the increasing role of new technologies, with therapeutic education programs using serious games of the « Minidoc » type, developed by the French Red Cross and supported in particular by La Fondation Paralysie Cérébrale. The idea is to immerse the child in his or



her care pathway, to give them the ability to understand, to give meaning to and to anticipate care. This kind of device repeats every step of the care pathway and allows the child to gain knowledge. A nurse is here to help with a touchpad allowing her to flash QR codes situated in different spots – even on the caregivers' blouses – and thus to access playful educational contents.



An augmented reality module on tablet allows the child to incrust virtual objects in real images of care captured by a webcam

Along the same lines, we also use hypnosis along with other methods.


Hypnosis is a natural phenomenon of letting go everyone is capable of. It's a very powerful tool, which demonstrated its effectiveness in treating pain and which can be helpful in the management of care-induced pain. For some children and adults with CP, because of their traumatic experience, it is more difficult to access it (this letting go), but it is always possible to reactivate this process through learning and training, sometimes with the help of a therapist.

For some children who experience these difficulties in letting go and who thus need control, the Minidoc device offers a second module using augmented reality to improve the management of care-induced pain. The touchpad allows the child to embed in a realistic manner virtual objects in the real images of care. These virtual objects have potential analgesic effects through hypnotic suggestion: the child can reduce pain, but also act virtually on the caregivers (sprinkle water on the practitioner for instance!), following the principle of counter aggression. By allowing the child to stay in contact with the reality of care, this device makes possible an adapted memorization of the treatment and reduced post-traumatic stress. There is an ongoing multicenter study to evaluate its impact.

We must develop training in hypnosis, serious games, but also raise awareness about coping strategies, and simple and adapted communication techniques capable of having a quick impact on the improvement of care in children and adults with CP.

The management of pain is an ethical and legal issue and care-induced pain must be considered a side effect of the treatments.

## 4- The revolution of rehabilitation

	<p style="text-align: center;"><b>Interview with Philippe Toullet</b></p> <p>Physiotherapist, co-founder of the Institut Motricité Cérébrale, Paris</p>
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Rehabilitation work changed a lot in the last 15 years, due to the progress of knowledge and shifts in approach. Philippe Toullet, who followed all these changes, decodes them for us.

The way we address disability, with a focus on participation in particular, changed a lot. Did that change rehabilitation?

Rehabilitation is part of the same movement: we moved from work based on motricity (we spoke of brain motor evaluation, of motor guidance, etc) to a much wider approach, motor rehabilitation being more and more in relation with the treatment of information and cognition. By referring to the ICF (see article 1), physiotherapists too ceased to focus on motor deficiency. Training programs associate motricity with perceptive, sensory and behavioural problems, and address the function and social participation besides deficiencies alone.

What is the concrete impact of rehabilitation on children?

The pedagogy of motor learning evolved in the same direction: we take into account how children approach and integrate the information brought to them, we are interested in perceptive and cognitive aspects as much as strictly motor aspects. We thus changed our techniques, which are now less analytic and more global.

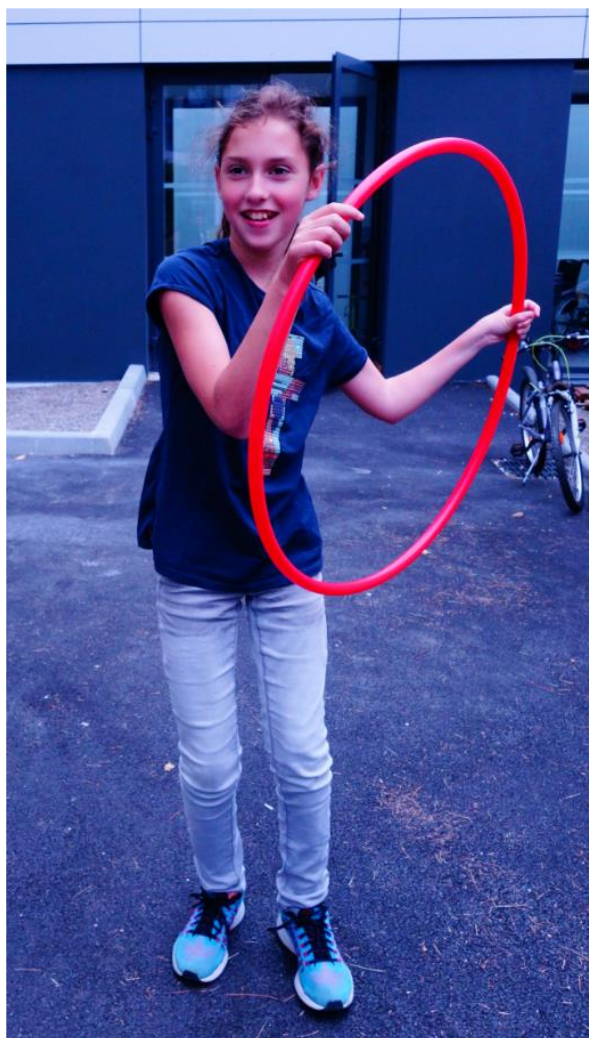
Teaching also includes creating the conditions for motivation: we must start from the person's needs to develop rehabilitation objectives that are playful (for the benefit of the moment) and at the same time respond to his or her aspirations for the future. So it changes the relationship between therapists, patients and families: we moved from a descending relationship to an interactive one based on science, experience and the subjects themselves.

Equipment also changed: we moved from passive techniques (in order to stretch muscles) to a more active approach. We seek an organic quality, equipment must be integrated in the subject's living environment to allow function, social participation, and finally contribute to a better quality of life. Equipment thus became functional – not only orthopaedic – tools, which must be socially integrated.

Likewise, we evolved a lot on the question of the intensity and pace of rehabilitation, in particular with the lessons learned from the HABIT-ILE intensive early rehabilitation method.

The importance of early rehabilitation was already mentioned in the 1980s, but the system did not necessarily follow. In the 1990s, we didn't want to tire the child, to preserve his or her childhood. Today we overcame this concern.

Finally, the physio « leaves the office », and the culture of physical activity spreads in the same way as in the general population. We want to integrate this trend in the daily life of the persons, in order to do that we offer them adapted physical activities for their leisure: swimming, muscle-building, but also climbing or circus!



We imagine that rehabilitation is also impacted by the evolution of other medical disciplines.

Indeed, and in particular by changes in the field of orthopaedic surgery. For instance multi-level lower limb surgery (which consists in intervening at the same time on different deformities rather than performing successive interventions) necessarily impacts the rehabilitation that comes with it. Same with surgical techniques for scoliosis: it's very possible that in 10 years, we'll have earlier interventions and no more corsets.

Progress in neurosurgery (selective dorsal rhizotomy), allowing to reduce spasticity, will necessarily transform pre and post-operative rehabilitation.

In a general manner, physiotherapy is involved in evidence-based medicine. We moved from the expert who bases his or her practice on experience to a rehabilitation where we are asking questions, investigating. It's a great step, we interrogate more and more our practices, and the result can only be improved.

Moreover this reflection allowed to validate the approach initiated by Michel le Métayer, who was a visionary, to whom we must pay tribute. In particular he's the one who gave their place to parents in order to define common objectives, ways of doing things so the stimulation of the child can continue outside rehabilitation sessions.

### Are there still things to improve?

The cultural change now taking place will lead to new improvements.

Evaluation of the objectives' procedures allow us to measure progress in an objective way. In parallel, patients and families increasingly demand an effective management of pain. All that opens the way for improved practices. But we see that this reflection is not as prevalent in other countries and that many children remain deformed and in pain.

Likewise, the place of parents isn't well established yet. They still have to fight to make themselves heard. But thanks to easier access to information, they are now familiar, sometimes more familiar than professionals, with the new emerging methods. If the caregivers don't pay enough attention to them, they will seek others.

Finally, we can consider that the training of physiotherapists in regard to CP improved a lot in 20 years: training in paediatrics got more thorough in the initial formation, and access to continuous training was facilitated in particular for private therapists, who take care of about 50% of people with CP (source: ESPaCe Study). It's an important step, but much remains to be done if we want to meet all expectations.

## 5- Technological changes in motor rehabilitation



### Interview with Dr Christelle Pons

Physical and Rehabilitation Medicine, Ildys Foundation (Brest),  
Research team BeAChild

Apps, virtual reality, robotics... Technology enters the field of rehabilitation for the benefit of patients and families. The perspective of Dr Christelle Pons.

#### What are the technological changes applicable to rehabilitation?

There are several kinds, with effects at different levels.

We can think of robotics, of virtual reality, which complete our tools for rehabilitation. But a simple smartphone can help improve the accessibility of care.

For that, the year 2020 with its restrictions allowed to experience new forms of care. The first lockdown initially caused a near-total suspension of rehabilitation care. Families and professionals rapidly sought solutions to continue with motor rehabilitation, at least partially. Families were very active to maintain home care, often on their own. Maintaining the link, even by phone, to help them manage and take over from the professionals, was appreciated. In some cases, virtual rehabilitation programs were proposed. We don't have evidence of effectiveness yet, but the first feedback seems to indicate that the experience was interesting and deserves further study.

This invites us to further reflect and study on the accessibility made possible by communication tools: knowing that 36% of the world population owns a smartphone makes us think that solutions for rehabilitation could be offered patients, whatever their location. And for the ones who can't use a phone themselves because of their disability, the carer might also be a coach. These solutions are promising, but must be validated, and implementing them will take work, in particular in terms of acceptability, or simply of integration in the health care system.

#### In the meantime, there are already innovative tools

Yes, and they allow us to respond increasingly better to the patients' expectations, and to support the progress of knowledge in the field of rehabilitation.

So we now know what is necessary for motor learning: functional objectives codetermined with children and families, repetition of gestures, intensity, shaping (that is adaptation to the child's progress), growing difficulty, proposition of feedback and motivating exercises.

Robotics are useful for everything relating to repetition and increase in individualized intensity; virtual reality also makes this dosing possible, as well as feedback through immersion in a virtual environment. In virtual reality, the use of software can support shaping.

These tools can facilitate in-home rehabilitation and thus be interesting in regard to a better integration of rehabilitation in family life. It means that families and children are actors of the decisions that are made concerning rehabilitation, and that practices and tools will have to adapt to their lives. So we will involve the persons concerned in these tools' design more than we used to, co-design being the ultimate goal.



### Does technology have an impact on the persons' acceptance of rehabilitation?

We don't have measurements yet, nor evidence on this, but the hypothesis is indeed that new technologies improve the persons' acceptance of rehabilitation, and their commitment to it. These tools often allow to make the repetition of gestures more « fun » for instance.

We believe it can also improve the effectiveness of rehabilitation: the method being more amusing, the child gets more motivated and more committed (and probably the adult too).

In the field of virtual reality, in Canada and in the United States, we measure more and more this commitment, to demonstrate that these new tools are interesting both for children and families. This topic is a key issue today, and even if we are a bit late regarding family-centered care, this research topic will certainly emerge in France.

### What are the other new things ?

Many innovations at the service of disabled people emerge. For instance the research team BeAChild is currently developing a mediation app for the therapist, the child and his or her family, in order to codetermine objectives and to measure progress. This tool will help implement objective-centered therapies, facilitate the therapist's work if this one isn't specifically trained in child rehabilitation by guiding him or her (to identify objectives), and to create a more transparent bond between the therapist and the family. We are at the « beta » version, probably launching by summer 2021 (the beta version is the last version of a software before its launching).

In parallel, families created collaborative platforms between associations, private individuals and companies in order to list these kinds of innovations.

Technological progress allows us to imagine many technical solutions capable of easing the daily life of the disabled, but there is still a big gap between what is offered the general public and what the disabled can access. Microsoft did develop an inclusive console, but this approach remains confidential. People must make themselves heard and say that innovative solutions aimed at facilitating their daily life are hoped for and expected. Hackathons on the theme of disability, which exist in certain engineering schools (EPF Sceaux, Montpellier, Troyes or EPLF Lausanne), could help convince it is a topic of interest. In that state of mind, a consortium, Innov4child, was created in 2020 to promote innovation for disabled children through actions of coeducation including patients, families, health professionals and engineers. La Fondation Paralysie Cérébrale is part of this consortium, along with several research teams (BeAChild, within the INSERM, CanChild, UMC Utrecht, the EACD (European Academy of Childhood Disability), engineering schools (EPF, EPFL) and hospitals (SERMAS, CHRU Brest).

The diffusion and accessibility of new techniques are key issues, and whilst everything is possible, much remains to be done.

### TESTIMONY

Pierre-Marie, accountant

I first studied in an ordinary school, the one of my district, until second grade. Then I switched to specialized institutions until graduation: it was a professional baccalaureate (Bac pro), followed by a Bac level 4 in a Motor Learning Institute.

Being in a specialized institution, with an onsite rehabilitation center, makes things easier in case of a problem. But even so all difficulties are not overcome: the year when I had to increase the number of rehabilitation sessions because I had problems, I missed a number of classes and wasn't able to fully catch up.

I really discovered an ordinary environment when entering the workforce. I had the chance to extend my internship in an insurance company: first it became a summer job and since everything went well, I applied at the end of my studies. When the company was bought by another, I got a position on a site closer to home, which allows me to shorten courses.

I benefit from the disabled-worker status RQTH, which means that a contract of 7 hours a day represents 6 hours of effective work. The time saved allows me to have extra-professional activities after my rehabilitation sessions.

Integration into society and in the workplace improved a lot, but I think it also depends on the companies. Mine is a mutualist company, sensitive to the question of disability because of its activity. So I feel supported, with a review every trimester, knowing that the management would help me with my problems if there were. I've worked here for a bit more than 8 years now.

My employer also knows how to adapt his demands to my competencies: he doesn't put me in trouble. Everyone is caring, accommodations are made for me, but above all I appreciate working with my colleagues.



## 6- Taking into account cognitive disorders in a better way



### **Interview with Dr Joel Fluss**

Pediatrician and neuropsychiatrist, Children's Hospital, Geneva

Long understudied, cognitive disorders affect very frequently persons with CP. Dr Joel Fluss explains their importance, especially in school, for the learning process.

### How do you explain that cognitive disorders are still relatively unknown?

For a long time, child health was defined essentially between two poles: physical health on the one side and mental health on the other side, which left behind the concept of « cognitive health ». Everything related to mental capacities (all things required to speak, to read, to calculate, necessary for the learning process) was removed from the « medical », it wasn't a part of the paediatric curriculum per se.

Since the 2000s, with the contribution of neurosciences and medical imaging, we've been able to understand more precisely how a (typical) child learns. In parallel, paediatric neuropsychology developed to answer growing questions about the reasons why some children didn't succeed in reading, calculating, or making certain gestures. This awareness of the importance of the « cognitive » in the global evolution of a child's health progressively expanded to include children considered at risk like very preterm infants, children with genetic anomalies or having suffered from early brain lesions.

For these ones, however, we realized that we couldn't reason like for adults (such lesion causes such deficit), nor limit the issue of CP to motor impairment alone. If a disabled child experiences difficulties, for instance in exploring the outside world, or in expressing him- or herself, the reason might not be just motor or joint problems: specific cognitive deficits, for instance in visuospatial perception, or troubles with lexical access, can also play a part. It is now accepted (in the very definition of CP) that underlying brain lesions, depending on their location and extent, cause disruption, the spectrum of which is very variable, and goes way beyond motor processes.

### You even speak of interdependency between motricity and cognition.

There is a concept in cognitive psychology: embodied cognition, which describes the essential entanglement between mental and sensorimotor functions. Our relation to the environment, our perceptions and actions are closely linked. This is particularly true in the development of the young child, who will comprehend the outside world using vision, audition and touch, and will thus understand intuitively the physical laws that explain for instance the movement of an object. This kind of exploration, the grasping of familiar objects like glasses, show that clearly: I know these are glasses (identification of the picture), I grasp them (which means I am able to evaluate the distance between me and them) and I put them in my nose (adequacy of the gesture and the intent).

Interdependency between cognition and motricity is also obvious for instance in spatial awareness: several studies highlight the fact that the persons whose independent mobility is reduced experience difficulties in following directions and locating themselves. To comprehend the outside world, we must explore it.

We also realized the importance of counting on fingers for the development of digital skills in the young child, since it makes possible an analog representation of numbers, a concept otherwise abstract. To quote the title of an Anglo-Saxon publication, we can say that « digits help digits ».

So not only can primary brain lesions be held responsible for cognitive disorders, but their impact is also functional. So we must keep in mind that a child with CP is not only affected on a sensorimotor level, the most visible, but also on the cognitive and on the sensory levels. Behavioural troubles sometimes follows.

### What are the consequences of cognitive disorders on these children when they grow up and start school ?

It all depends on the degree of these disorders, on their nature, and on how early they were identified. Often attention problems, issues with visuospatial perception, drawing, writing, as well as a weakness in mathematics, are the elements that call for vigilance.

In the case of a « slight » motor disorder, in walking children, these difficulties often take precedence over the motor issue at school age. For parents, it can be difficult to accept: they thought they « got out of it », so it requires a new effort to accept these differences in learning skills. It is also difficult for the teachers, who are sometimes insufficiently prepared to deal with a disabled child, even more when it's « slight », and to understand the issues surrounding his or her schooling.

On the contrary, children with severe motor deficiencies, often non-talking and non-walking, can show more skills than expected. The auxiliary means they are provided with (for mobility), their ability to use

machines, will allow them – sometimes to everyone's surprise – to better understand their environment and to better communicate with it. So the question is: how do we put forward this underrated cognitive potential so they can interact with the outside world, flourish, and even carry out a professional activity. For that the ICF classification, which is pragmatic and essential, helps identify everyone's potential. Finally, in the middle, we have children with an obvious but moderate cognitive handicap, who will study in an adapted environment, whose situation will sometimes be more « simple » than for children less impacted because their disorders, including the cognitive ones, will have been rapidly and correctly identified.


#### How can we make sure that all children get their chances ?

An effective interface, implemented early, between the educational and the medical world, is essential, since the partitioning of our society and of our consultations sometimes widens this gap. It often happens that the medical world evaluates disabled children with ill-suited tools, without regard to everyday life, which makes all conclusions on cognitive functioning null and void, with no functional perspective. The educational world, for its part, doesn't necessarily take into account, out of ignorance, the specificities of these children. Finally, despite technological progress, the tools developed to help these children remain difficult to access and unfamiliar to most involved in care. Engineering laboratories dedicated to the disabled are still far from the educational environment. Yet assistance provided from an early age to the most severely hit children could be invaluable.

The ideal might be the creation of more bridges between practitioners, therapists, specialized teachers and engineers to think about the children's needs, in a concerted manner, in multidisciplinary consultations for instance. It is sometimes surprising how long a non-walking child must wait before an electric wheelchair is offered him or her, while he or she already uses a smartphone with ease. Today, in an adapted environment, children have the possibility to show themselves more proactive and autonomous.

The ultimate goal is to help disabled children flourish and find their place in society like everyone else.

## 7- Better knowledge for a better inclusion

	<p style="text-align: center;"><b>Interview with Pr Régine Scelles</b></p> <p>Psychologist, Psychological and educational sciences, Paris Nanterre University</p>
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The French Disability Act 2005 on equal rights and opportunities, for a better acceptance of disability and a better participation of disabled people, led to real progress. But the lack of studies in certain fields or continued deadlock still represent obstacles for a really inclusive society. The perspective of Pr Régine Scelles

#### What progress was made in the last 15 years?

We can consider two major evolutions.

The first concerns family. The birth of a disabled child upsets the whole family and we made progress in knowing what happens here. We broadened the field of study, we came out of the mother-child



« bubble » to take an interest also in what fathers live: they are more present, which has a positive influence on the child and the whole family at the same time. Likewise, brothers and sisters step out of the shadows, they are listened to: for instance the Centers for Early Medical and Social Action (in French CAMSP) take into account both what siblings experience and the disabled child as a brother or sister.

The other good thing is that society is more and more inclusive, or wants to be. Inclusion at school progressed a lot, but certain fields remain forgotten: such as life in the city and leisure, these challenges are still ahead of us. This last issue is particularly important for teenagers, who could experience positive inclusion through leisure despite difficulties at school. We must also ensure a certain balance: even if it is important that disabled children are included, we must also give them the opportunity to meet with other children with deficiencies so they won't always be the ones struggling.

### Disabled people also start to make themselves heard

It is very important that they can decide for themselves, define their needs, « speak and not be spoken for ». In disability studies we sometimes find this phrase: « not a thing for us without us ». This movement is still shy in France, however disabled people start to play a greater role in decision-making bodies. For instance, organisms like the CNSA supports certain research provided that there is a real partnership with disabled people and that they are members of the steering committees. This movement is quite powerful in Quebec for instance, but it still meets resistance in France, where we often hear « the parents » when we say « the persons concerned ».

In a different register, it is important that disabled people can explain what their competencies and abilities are. There is what we call the theory of stigma: a deficiency may lead others to assume the existence of other deficiencies through a kind of halo effect. On the other hand, not taking into account the deficiency is also detrimental. We shouldn't want disabled people to be « like the others »: they must be recognized and accepted for what they are, without feeling the need to conform to the standard. « Give us a place for what we are », say many people with disabilities.

There is still much to do in this field. The vocabulary is also an issue: we now know what an inclusive society must not say (anymore), but we don't always know what to say instead. This difficulty reflects the fact that society still reflects on how to call these persons.

### What are the other areas for improvement ?

There is a lot of work on the child, but we lack studies on teenagers, with their specific problems, and even more on adults. The topic of parenthood is not studied at all for instance. Yet it is a very important subject: how do disabled people see themselves as parents ?

Regarding teenagers, the organization of the research system is an obstacle to the diffusion of studies. Papers are published by discipline while we need a multidisciplinary approach to understand adolescence: we need psychology, sociology, anthropology, all social sciences. This lack of studies can make us overlook certain kinds of mental suffering.

In a general manner, we must keep in mind that the way we deal with children and teenagers has an impact on the persons they will become. When you hear all your life « eat better, walk better », when a child has trouble expressing his or her pain while their body hurts all the time, it affects one's personality.

We still have to improve our understanding of the environment, of what disabled children, teenagers and adults go through, and of how these factors impact their ways of being.

