

Peder Esben

# ”NEW CP”



## Cerebral Palsy - hold to the light

A modernized approach suggests  
a new definition of cerebral palsy

Now is the time for a paradigm shift



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Published by:  
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Print: P.J. Schmidt A/S, Vojens, DK

ISBN: 87-90936-05-1

## Preface

Cerebral Palsy is the most common diagnosis of congenital brain damage. It is often described as an 'umbrella term' comprised of several different syndromes (Mutch et al. 1992). Cerebral palsy is considered one of the most severe disabilities in childhood and has a strong impact on families and children themselves. Moreover cerebral palsy makes heavy demands on health, education and social services. The life expectancy of children with cerebral palsy is increasing worldwide, even among children with a severe level of impairment (Hutton et al. 1994).

Thus cerebral palsy is associated with life-long disability where need for services will be high, which means that appropriate services will need to be provided through adolescence and sustained into adulthood. Many young adults with cerebral palsy have severe problems due to reduced contact with health services after leaving schools (Bax et al. 1988). Likewise young adults with cerebral palsy often face considerably difficulties in integrating into society (Thomas et al. 1988). In this country there is no structured health and care programme for these adults after the age of 18 years.

Very recent research done by the Danish Cerebral Palsy Register shows that within a population of 800 adults with cerebral palsy born 1965 – 1978 only 29% - (3 in every 10) - are self-supporting. *(to be published approx. Nov. 2003).*

In an attempt to comply with this situation The Danish Society for Cerebral Palsy initiated a study programme called CP•Centre performing analysis, counselling and research for adults with cerebral palsy.

The review study comprised in this booklet is based on inspiration from the findings generated within this research programme.

The conclusions of the CP•Centre showed that cerebral palsy per se has a strong impact on the interaction of psychological – perceptual – cognitive functions. These findings were contrary to the fact that all known definitions of cerebral palsy mention only impairments of movement and/or posture and disorder of motor function (SCPE 2000). Therefore we organized a search within the medical literature in order to ascertain if other centres, scientists etc. were engaged in similar kind of studies and if possible had reached similar results as those of CP•Centre.

Slowly a new world opened in relation to cerebral palsy. The many roads of searching both lead far and wide geographically, and a long way back historically.

It became obvious that the findings of CP•Centre were in consensus with those of several groups of scientists. In historical retrospective, parallelism could be established all the way back to

Freud who was among the first to point out that cerebral palsy is more than merely a motor disorder.

This effort of research and uncovering made it evident that cerebral palsy has become a vague diagnosis, which nowadays primarily equals motor disorder.

From the experiences of the work within The Danish Society for Cerebral Palsy we know that this conception does not in any degree match with reality, but it is only now that we are able to show and explain why and how.

That cerebral palsy originates from a brain damage is a well-known fact – but assuming that this damage should confine itself to manifest only as a motor disorder seems to go against the very nature of a brain damage.

With the results of CP•Centre as basis combined with recent international research and historical retrospect this booklet gives voice to the point of view that a fundamental change in conception and comprehension of cerebral palsy is urgently necessary– a paradigm shift is essential i.e. an entirely basic and thorough modification, which consequently will entail a new definition of cerebral palsy.

If this is not recognized we risk staying confined within present practice, that over focuses on the motor impairment of CP but leaves the psychological and cognitive element with a lower priority.

The implications could mean reduced possibilities for people with cerebral palsy in relation to therapy, an accurate self-concept, inclusion and participation in education, job opportunities and social interaction. ■

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*July 2003*

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## Summary

The conclusions from the CP•Centre together with relevant neurological research suggest that the syndrome cerebral palsy – in its most basic manifestation - not only results in physical motor disorder, but also involves specific cognitive deficits [1,2,3]. Moreover the specific cognitive deficits seem to be of great influence on the quality and function of life for people with cerebral palsy.

This fact is of fundamental importance and indicates that the following issues must be taken into consideration within the future conception and interpretation of cerebral palsy:

- that specific cognitive deficits are of considerable greater consequence than assumed within the present conception of CP.[2,7,8]
- that early treatment and therapy regarding CP must include cognitive functional training and development of competence.[1,6]
- that specific cognitive deficits are seen to be of greater significance in relation to quality of life, social and occupational participation and self-concepted degree of impairment than motor disorders.[2,4]

Thus evidence strongly suggests that this knowledge must be implemented in the automated general treatment options and therapy programme for children diagnosed with cerebral palsy.

Based on the psychological test results from CP•Centre combined with comparative research it has become obvious, that the very act of perception seems to be damaged or disrupted in cerebral palsy.[14,34] Recent studies indicate that the brain damages, prior to cerebral palsy, are often found in the deep-lying areas of the brain's white matter around the brain nuclei where supporting handlings for the perceptual functions essentially are concentrated. [25,26,26A,35]

Present diagnostic practice implies the risks to over focus on the motor disorder, whereas this should rather be looked upon as part of the complexity of the syndrome cerebral palsy per se.

Consequently it is urgent that an improved and more distinct definition of cerebral palsy is introduced.

Treatment and therapy must seek to elevate and enhance abilities, social interaction and quality of life for people with cerebral palsy. Focus and training programmes must include cognitive as well as motor functions, which presupposes intention and aptitude for consistent adoption of interdisciplinary diagnostics, treatment and cooperation. ■

## CP•Centre - a research programme (completed Oct. 2002)

CP•Centre was primarily based on the fact that there is no structured treatment and therapy programme for adults after the age of 18 in Denmark.[9] Furthermore new knowledge inspired the onset of CP•Centre – first and foremost the fact that the human brain possesses great dynamic and plasticity and both in principle as in practice can be treated and improved all through life.[10]

CP•Centre was a programme for adults with cerebral palsy over the age of 18 with the main object of guiding and counselling the individual. The intention was that each person would be capable of participating in daily social activities and if possible should find the proper placement within work, education and level of activity.

The design of the programme was based on an individual model i.e. every client was described and analysed based on individual abilities. Furthermore the study was done as a phenomenological, empirical programme on a selected group of adults with cerebral palsy.

Even so comparative research based on the compiled data set from the programme was carried out in order to focus on general tendencies.

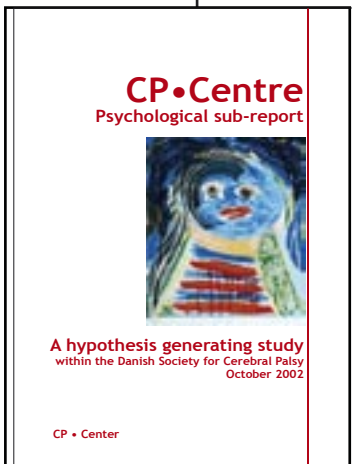
This research made it evident that especially within the field of psychology the CP•Centre could shown some very interesting general results that could contribute to developing and expanding the conception and interpretation of cerebral palsy.

All clients in the programme (28) were examined by a neuropsychological test battery (WAIS-R).

Conclusions from the psychological sub-report of the programme state:

1. the brain damage manifested in cerebral palsy seems to be of a perceptual origin involving specific cognitive impairments.
2. IQ (intelligence quotient) is inadequate to express the cognitive functions in people with cerebral palsy.
3. individuals with cerebral palsy should get psychological appraisal early in life, as it is of vital importance to begin adequate training of the cognitive functions as early as possible.
4. the necessary resources must be made available within school and education to compensate the specific cognitive impairments.

The psychological appraisals show a distinct pattern in all of



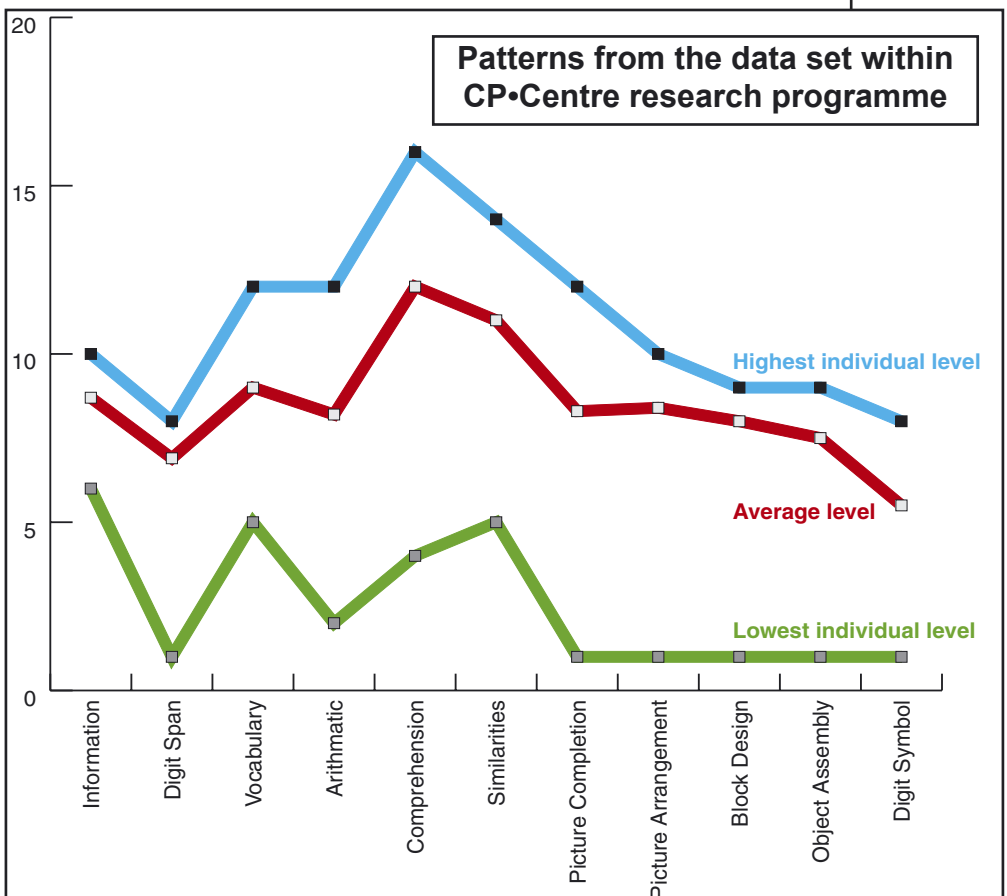
**Exhibit A**  
**page 28**

the tested persons – irrespective of individual level. A closer interpretation and pattern analysis suggest an underlying perceptual brain damage. The specific cognitive impairments are seen within four main categories:

- ❑ concentration
- ❑ ability of combination and structuring
- ❑ completing a task or sequence
- ❑ short-term memory

The fact that the cognitive deficits are so specific and delimited indicates that the natural history of cerebral palsy does not involve general mental retardation – though some children with CP may have mental handicaps on top of cerebral palsy. Moreover this fact makes it obviously impossible to interpret the cognitive deficits from an overall calculated IQ figure.

Basically the data from the psychological appraisals demonstrate that the phenotype brain damage, which causes cerebral palsy, implies impairment of perception involving both specific motor and specific cognitive symptoms. ■



*This figure shows three patterns deduced from the WAIS-R data set on all the clients participating in the CP•Centre research programme. The similarity between the curves is evident. So the patterns from the highest, the lowest and the average level are directly comparable, which supports the theory that individuals with cerebral palsy present specific cognitive deficits irrespective of individual IQ-score per se.*

## From around the world

Researchers, experts and groups around the world arrive at similar results and conclusions as those of the CP•Centre.

The Italian professor of neurology Giovanni Cioni from the University of Pisa has in cooperation with colleagues carried out research in the relationship between visual impairment and CP. He finds that children with CP often show difficulties in perceiving and converting visual impression accurately into cognitive usable information.[1,12]

Perception (e.g. sense of movement) as a **multisensorial** process. The brain produces **coherent** interpretation of these multiple perceptions. The brain uses **several systems of reference** for perception, in relation to the task to be accomplished, and to sensory indexes available and more useful. **Body scheme** represents the sum of these reference systems. The **memory** of previous movement perceptions (located in the hippocampus, the prefrontal and parietal cortex) is essential as a guide for future action.

### Main perceptual (sense of movement) disorders in CP (Ferrari, 2001; Ferrari and Cioni, 1997)

Sensory information are reduced. Sensory information are available but the child has difficulty to treat them because of:

- difficulty to pay attention to sensory information, and/or to sustain attention to them for sufficiently long periods.
- difficulty to put them within a coherent framework (as in vertigo), and/or to modulate perception through an anticipatory control on the sensory receptors or higher centers (information become excessive, or discordant often unbearable).

### Conclusion

Perceptual disorders in CP are not "associated" disorders, but important factors for understanding the natural history, the motor symptoms of a child with CP and for treating them.

He shows that this condition is not due to damage of either the eye itself or the visual pathways in the brain or the cortical visual centre but rather must be put down to the perception of visual sensation. The brain is not able to percept – „treat coherently“ – the sense impressions accurately. This deficit is believed to originate from the brain damage, which causes the syndrome cerebral palsy.[1,11]


Using vision as basis and example Giovanni Cioni shows that the perceptual function in children with CP is specifically reduced, which indicates the presence of other specific perceptual deficits, too.

A reduced perception means lacking in ability to sustain sense-input, concentrate and apply previous acquired proficiencies and skills.

An obvious conclusion is that perceptual damage not only causes specific cognitive deficits but also motor disorders, which is coterminous with the fundamental believe that cognition as well as motor function is controlled by and dependent on the perceptual system as such.[13,14]

3 key slides from a lecture by professor Giovanni Cioni.

Professor in paediatric neurology Brian Neville of London has both in papers, books and lectures expressed the point of view that CP is a very complex syndrome which as a fixed term calls for re-evaluation if we still shall be able to use this designation as a merely moderate exact diagnosis or characteristic.



He emphasizes how important it is not only to consider CP as a motor disorder, but also to involve both the cognitive, learning and psychological behavioural aspects in CP in an attempt to establish an improved understanding and awareness of CP, which in their turn will lead to a broader entirety-orientated strategy for treatment. This increases the possibilities for people with CP to achieve an enhanced quality of life and an improved level of function.[2]

It seems quite obvious to Brian Neville that what the present diagnostic practice calls associated disorders – especially the cognitive – must be integral to the definition and characteristic if CP shall make any sense and have a chance of surviving as an original diagnosis.

As Brian Neville so accurately put it himself in a congress lecture: *„It seems crazy to throw out evidence just because we seem to have fastened on a motor disorder“*. [2]

The entire psychological behavioural pattern in a person with CP has an enormous influence on the possibilities for this individual to participate in full family, social, job and educational activities as well as ordinary life of the community. This is part of the fundamental thesis in studies and research done by the Israeli child psychologist and psychiatrist Abigail Golomb who in several papers has pointed out how essential it is to introduce the psychological aspect of cerebral palsy – both to the family, the relations and to the disabled individual.[4,5]

Some of the most momentous is mourning.[15,16] Both the disabled individual, the family as such and in particular the parents are struck by grief when it becomes a fact that the diagnosis in question is cerebral palsy. To make life with cerebral palsy as genuine as possible mourning is of the outmost importance. This process is essential for both parents and child to reach acceptance and awareness of the disability. If this process is put aside many will be induced to block out the fact of being disabled which could result in a situation where endeavour and focus are so narrowed down to being normal that demands and expectations toward the disabled child become unrealistically high, which often leads to daily defeat and frustrations. According to the research of Abigail Golomb it is vital for parents and the disabled child to recognize the limitations that exist because of the impairment and this can only happen if the mourning has been lived through.[4,5,17]

By accepting the impairment – its strong sides and especially the limitations – it becomes possible to live with CP and to find your right placement within social interaction and participation.

If acceptance and awareness of own impairment are incomplete it is often seen that the child is incapable of conforming to the daily life in a realistic manner. ■

(see exhibit B - page 34)

## A brief historical retrospect

Cerebral palsy is by no means a new syndrome. Most likely children with CP have been born for as long as children have existed, but the medical world did not begin to study the syndrome scientifically till the middle of 18th century.

For more than 150 years the conception and definition of CP have - in the main - been subdued to two polarized attitudes and conceptions.[18]

### 1.

The English surgeon William John Little was the first to describe and define the impairment later to be known as cerebral palsy. This took place in the beginning of 1860th and the syndrome was then named „Little’s Disease”. [19] The English physician Sir William Osler introduced the term cerebral palsy as late as 1889.[20]

Dr. Little believed that the causes of cerebral palsy were to be found in obstetrical complications at birth resulting in lack of oxygen to the brain. He claimed that this anoxia damaged brain tissues controlling the movements. This conception has in many ways lasted till this day and age and are still found with both therapists, relations and the cerebral palsied themselves.


### 2.

As early as in 1897 Sigmund Freud - then paediatrician but later world famous as a psychiatrist opposed this conception of CP. Freud noted that children with CP often had other deficits than the physical motor ones such as learning disabilities, mental retardation epileptic fits and visual impairment. He expressed the opinion that the brain damages, which cause cerebral palsy, must have happened early in life prior to birth - while the brain was in a violent process of growing during foetal stage.[21]

Despite Freud’s observations Dr. Little’s conception of CP remained the general accepted among doctors and other therapists. This situation was not fundamentally tampered with till the beginning of 1980th, where a very large American study covering more than 35.000 births could establish the fact that only approx. 6 - 10 % of the CP cases directly could be linked to damages occurring during birth or immediately after. The rest derived from damages to the developing immature brain during pregnancy.

The psychological aspects and the cognitive deficits of cerebral palsy receded into the background when Freud’s point of view about the complexity of CP was not generally recognized or accepted.

However several scientists have since then studied the psychological / cognitive elements of cerebral palsy. Psychologist



Elisabeth E. Lord at Children's Medical Centre in Boston did some of the earliest research and work on this - in 1929. She demonstrated the importance of individual psychological test and appraisal, but she also showed that ordinary psychometrics such as IQ were unsuitable in relation to cerebral palsy because of the characteristic nature of the brain damage resulting in both motor and cognitive manifestations. These studies were published in 1937.[22] Later another psychologist Edith Meyer Taylor (1959) published papers which supported the theories and findings of Lord.[23]

The American orthopaedic surgeon Winthrop Phelps published a paper in 1948 [24] in which he presented the assumption that the prevailing part of children with CP had normal IQ or above, thus contributing to over focusing on the physical motor element of cerebral palsy. As was the case with Dr. Little in 1860th the conception that Dr. Phelps introduced became the prevalent one, and this situation has - unfortunately for persons with cerebral palsy - lasted to the present time. ■

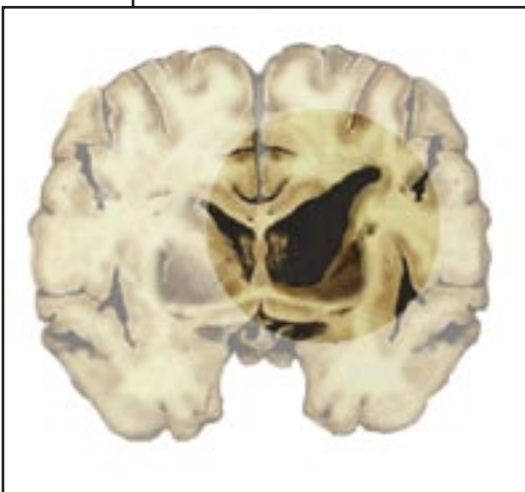
## Brain damages and the aetiology of cerebral palsy

Nowadays it is widely accepted that the majority of the brain damages that lead to cerebral palsy has occurred in the immature developing brain before birth – predominantly between 26th and 32nd week of pregnancy.[25,26,26A]

Moreover only a few characteristic types of brain damage are seen to be the background for or a strong contributory cause to the greater part of cerebral palsy cases.[27,28]

These types of brain damage either cause a kind of degeneration or crumbling of brain tissue, or cause haemorrhages in brain tissue, which involve malformation and dysfunction.

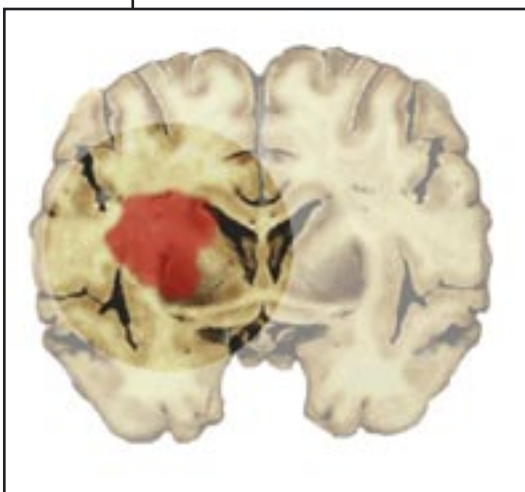
The damages mostly occur within the white matter brain tissue in the deep-lying areas close to the ventricles of the brain. Both types result in varying degrees of damage to the brain tissue and the nerve fibres, which means that the extremely complex communication that takes place between the different areas of the brain and centres is injured.



### **Periventricular Leucomalacia (PVL)**


*This figure shows drawings of the two most common brain damages found to be integral in cerebral palsy. The top drawing depicts a type of brain damage called periventricular leukomalacia (PVL), which degenerates the white matter and causes reduced function in the area.*

*The drawing below shows another example of brain damage in cerebral palsy. This type is called periventricular haemorrhage (PVH). It causes bleeding in the white matter tissue deep in the brain destroying neuro-communication in that part of the brain.*



### **Periventricular Haemorrhage (PVH)**

The damages result in quite severe complications. Basically they inflict interruptions or literally destructions to the numerous nerve fibres that bring information (the so-called projections)



back and forward between the deep-lying brain nuclei - combined named the basal ganglia - and the communication links from the basal ganglia to the higher centres of the brain cortex.

An accurate perception of sense-input is the essential pre-action for both motor and cognitive functions to succeed, and exactly within the areas close by and between the brain ventricles several brain nuclei are found which must be in constant connection - partly with each other partly with centres in the brain cortex - as a preliminary condition for perception to progress accurately. Consequently damages in these areas will have substantial influence on the perceptual function as such i.e. interpretation and control of sense impulses, which can imply reduced cognitive and motor functions.[14,29,30,31]

When brain tissue is injured the numerous nerve-signal-pathways (projections) that runs between the basal ganglia and the brain cortex will be damaged, too and this results in reduced perceptual ability.[26A]

Among the symptoms from these types of brain damage are most importantly a reduced overall attention and capacity of sustaining attention. More specifically are lacking in capacity for completing a process, absent concentration and imbalance of tonus (tightening) in the muscles.

While the brain is growing – during pregnancy – the tissue around the ventricles is the place where new brain cells are formed that later will develop and become specialized cells in the outer layer of the brain cortex.

If the tissue around the ventricles is damaged prior to the production of these cells this could imply dysfunction and deformity of the new cells later to be part of the higher centres in the brain cortex, which again could decrease functions in these centres. ■

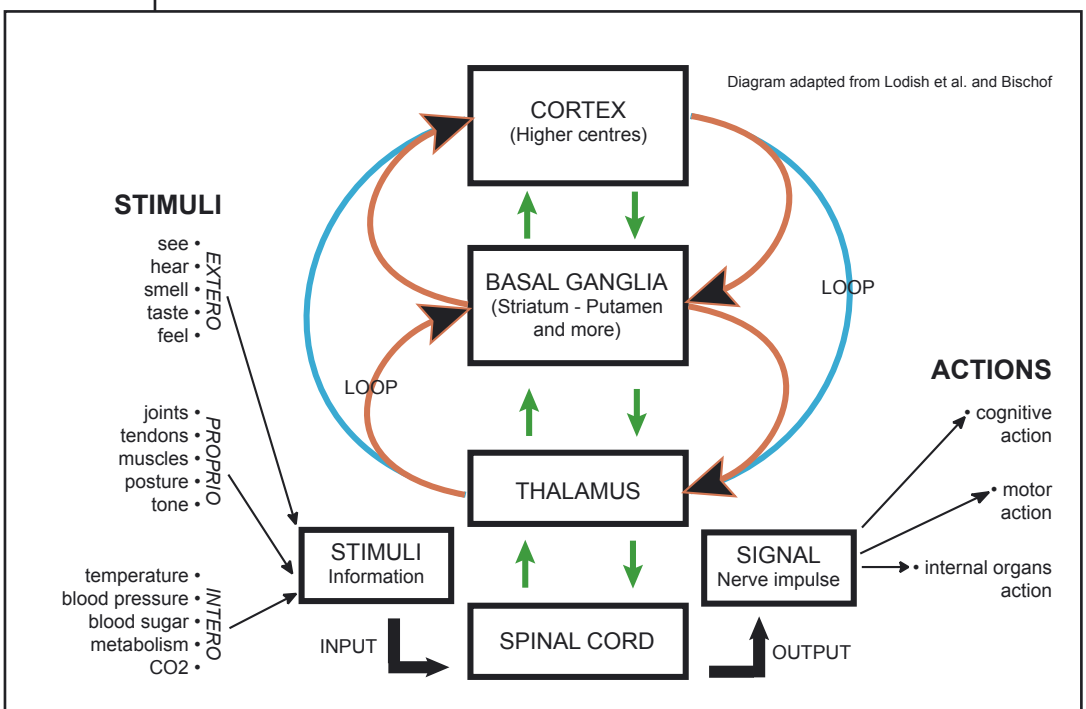
## Perception

### – what happens prior to motor and cognitive functions


As part of the syndrome cerebral palsy the motor disorder is quite obvious, while the cognitive deficits are somewhat more invisible even if they have wide influence on a person's self-knowledge and possibilities for participation and inclusion in general social relations.

Especially in milder cases of cerebral palsy the cognitive deficits will show pronounced greater consequences than the motor disorders.[2]. In both cognitive and motor action the underlying perception must be performed totally accurate for an individual to be able to function properly.[3,33]

From the psychological test results of CP•Centre combined with comparative research it has become evident, that the very act of perception seems to be damaged or disrupted in cerebral palsy.[14,34] Recent studies indicate that the brain damages, prior to cerebral palsy, are often found in the deep-lying areas of the brain's white matter around the brain nuclei where supporting handlings for the perceptual functions essentially are concentrated. [25,26,26A,35]



A figure of the process of perception. The sense-stimuli (input) come from respectively the outer world (extero), the body itself (proprio) or the internal organs (intero). The stimuli are converted in receptors into actual information communicated via nerve fibres. All input information are lead to the brain nucleus thalamus – a central area deep in the brain that handles all input as well as all output information. Thalamus is in constant connection with both basal ganglia and the brain cortex via direct neuro-pathways (—) and via so called projections or loops(—, —). Information travel continuously within this very complex network to regulate and prepare the output signals, which result in an action.



The perceptual process holds the global task of organizing, controlling and managing all the sense-stimuli that are received in the brain. The collation of sense-input involves among other acts selecting, regulating, increasing or inhibiting, integrating memory and simulating the action expected to be the final result of the perception.[29,30,33]

Information concerning all these sub-processes must go through and finally be compiled in the brain nucleus thalamus before a signal on action in the form of a nerve impulse can be transmitted to either the motor or the cognitive system or the internal organs.

So it seems rather important to involve the overall damages in the perceptual process as a precondition in understanding and comprehending the syndrome cerebral palsy. In that way a broader and more correct definition of CP can be obtained and recognition of the consequences in relation to people who are forced to live with cerebral palsy[1] ■

## **The specific cognitive deficits in cerebral palsy**

The psychological tests in CP•Centre demonstrated some distinct patterns, which suggest that people with cerebral palsy generally experience specific cognitive drops and deficits irrespective of overall gauged IQ, schooling, education or social status.

The drops (low scores) form a significant pattern, which indicates the presence of specific cognitive deficits. The size of the drops varies and the impact is altogether individual. The tendency however is evidently general, noting that the higher a person scores within the unaffected subtests, the more distinct the actual drops appear – while for persons who score low in almost all subtests, the drops become quite vague.

If an individual is psychological appraised from the numerical quantity of an IQ scoring, particularly with a high overall IQ score, drops will become almost invisible, because the IQ value is estimated by calculating an average. Relying on IQ values could lead to an incorrect interpretation of individual abilities and result in wrong or lacking support within school, education and job.

An overall IQ score is therefore of inferior interest and is quite simply considered useless in relation to cerebral palsy. In severe cases of CP the risk is to overlook the strong sides of an individual while in the milder cases the risk is that the weak sides will lack sufficient attention.

The specific cognitive deficits primarily manifest themselves within the following domains:

- ❑ 1 - concentration
- ❑ 2 - ability of combination and structuring
- ❑ 3 - completing a task or sequence
- ❑ 4 - short-term memory

### Regarding 1 – concentration:

The difficulties within concentration are seen as lacking in the ability to sustain attention towards a present task, an oral or written instruction or presentation, an individual contribution and moreover within social interactions like conversation, mutual experiences or teamwork.

Also the declined ability in concentration is observed in daily doings like reading (books, papers, TV-subtitles etc.), writing (letters, light papers, debating points etc.) and computer work (understanding an operating system or general software, acquiring basic PC-knowledge etc.).

In situations of learning and training – both motor and cognitive – the lacking in concentration is known to reduce the effect of the therapeutic effort.



Regarding 2 – ability of combination and structuring:

Especially within school, education and work the insufficient capacities within combination and structuring become obvious and manifest themselves. In situations where projects are to be planned, formulated and carried out within an independent, individual method of working – for example papers, light dissertations, applications, budgets, inventory control, logistic tasks etc. – a person with specific cognitive deficits from cerebral palsy will experience great difficulties or at worst have to give up the task.

Attending a lecture may cause some problems when the material from the lecture is to be worked up as notes later to be used in the process of studying an entire subject.

Regarding 3 - completing a task or sequence:

One of the lacking abilities, which is seen to affect people with cerebral palsy mostly, is the capacity to sustain attention and interest for a sufficient period of time to be able to complete a process and reach a result.

This lack of ability means that people with cerebral palsy often will find it difficult to finish even a fairly simple task and these kinds of difficulties are also very likely to be observed in connection with courses or processes of long duration like writing an essay, finishing a project or completing an education as such etc.

Frequently cerebral palsied persons will – describing these problems - state that the material or the contents of a given course is uninteresting, generally bad or simply boring as the reason why the course or the process is not finished.

Regarding 4 - short-term memory

Living with a poor – or perhaps variable - short-term memory can cause considerable consequences in relation to general functions.

Troubles remembering instructions, briefings or messages are typical. The surroundings often wonder why a person with cerebral palsy over and over again is able to follow an instruction or direction at one time, but can't do the same task some given time later - as would be expected.

In a direct learning process the reduced short-term memory means that persons with cerebral palsy must have new material repeated several times in order to understand, experience or acquire actual learning. Even after thorough directions problems like for example finding your way through a building or part of a city is often observed in persons with cerebral palsy - suggesting an insufficient short-term memory or working memory.

Surroundings will frequently misinterpret these problems as contrariness, lack of motivation and interest or indifference and apathy. ■

## **Children and the specific cognitive deficits**

As a basis children with cerebral palsy will present the same pattern of specific difficulties as the ones seen in adults with cerebral palsy.

Furthermore children will show additional specific characteristics within the syndrome cerebral palsy. Especially the psychological behaviour pattern call for attention inasmuch as children with cerebral palsy will experience innumerable situations where they are confronted with the fact of being different without being prepared how to manage such experiences.

The time of occurrence of the brain damages that lead to cerebral palsy is for the main part prior to birth, while the remaining part occurs during or immediately after birth.


So a child with cerebral palsy will experience being „born“ into this world as normal without any awareness of being different, as it is impossible for a child before the age of 8 – 10 years to proportionate his / her own identity to the surroundings and „discover“ being different.[4,7,8,16]

Before such realization can turn into actual acceptance or awareness of own situation an often long but in any case rewarding and meaningful development of competence is required.

This development is of vital importance and should be lived through as soon as the child's process of maturing has reached a stage where it is possible. Acceptance of own situation recognizing both strong and weak sides is vital for a harmonious adult life with cerebral palsy.[5,15,17]

During preschool age it is essential to keep in mind that the child with cerebral palsy will develop slowly in practically all fields. It is equally essential to keep in mind that for the majority of children with cerebral palsy this it is not a question of general mental retardation, but on the contrary merely a slow down during development in relation to time. When it comes to motor development this is very noticeable why once again it is important not to forget the more invisible specific cognitive deficits.

During the formative years an over focus on the physical motor symptoms is often experienced but in relation to the further development of the child's abilities and competence within school, education and social interaction it is vital that the adequate special therapy programmes for functional training of the cognitive impairments are made available.



An individual programme - if necessary in the form of special education – is essential for the majority of children with cerebral palsy and, as a minimum special education should be available as an offer and a choice.

In any case it is important that children with cerebral palsy are given optimal attention and offered the right stimulating environment of learning both within home, day-care, kindergarten and school. [17] ■

## **The future strategy for a structured treatment, therapy and training programme in cerebral palsy**

The fact that cerebral palsy involves specific reductions within the cognitive functions suggests that this knowledge should be implemented in the automated general treatment options and therapy, offered to children diagnosed with cerebral palsy.

From the conclusions of the CP•Centre and recent neurological research it seems evident that the syndrome cerebral palsy not only results in physical motor disorder but also involves specific cognitive deficits, which are seen to be of great influence on the quality and function of life for people with cerebral palsy.

This knowledge is considered to be of major importance and rather fundamental in relation to cerebral palsy i.e.

1. the specific cognitive deficits are of far greater influence than assumed within the present conception of cerebral palsy
2. early treatment programmes for cerebral palsy must include functional cognitive training and therapy and
3. the cognitive symptoms are of greater impact in relation to quality of life, social participation and self-realized degree of impairment, than physical motor disorders.

It seems both important and very essential that the conception, the comprehension and the interpretation of cerebral palsy are fundamentally changed. What is needed is an actual paradigm shift – which will lead to a new definition and a new characterization of cerebral palsy.

Today the perceptual–cognitive element is still a non-existing part of the definition of cerebral palsy. Consequently therapists, parents, relatives and the patients themselves continue to look upon cerebral palsy as primarily a physical motor disorder.

A definition has a fundamental impact on management and therapy standards due to the consequences on appropriations and the economical resources.

A definition may only consist of a few words but it lays down the basis for the general conception of cerebral palsy and more importantly it charts the course and limits of the appropriations and funds for research, management and therapy in relation to cerebral palsy.

Adding the specific cognitive deficits to the definition is of crucial importance to people with cerebral palsy in as much as tradition and lack of progress has left the focus on a motor disorder i.e. the outer visible symptoms of cerebral palsy. Consequently the treatment of cerebral palsy is still concentrated as a symptom-based management and therapy.

It is evident that cerebral palsy originates from a brain damage and it seems very likely that the damage which occurs in the immature developing brain implies perceptual deficits in relation to controlling and guiding the movements (motor function) and the process of thinking (cognition).

The outer visible symptoms are of course the motor disorder with the characteristic involuntary fluttering or sudden movements while the invisible symptoms comprise lacking in concentration and reduced ability of combination, structuring and organizing. Also short-term memory will suffer some degree of impairment like the capability to complete a given process – whether short (e.g. an essay) or long (e.g. an actual education).

In consequence The Danish Society for Cerebral Palsy will work determinedly for a paradigm shift, which involves a new definition of cerebral palsy with the perceptual cognitive element made integral and resulting in quite extensive changes and improvement of treatment and therapy, which ultimately will lead to a better life for individuals with cerebral palsy.

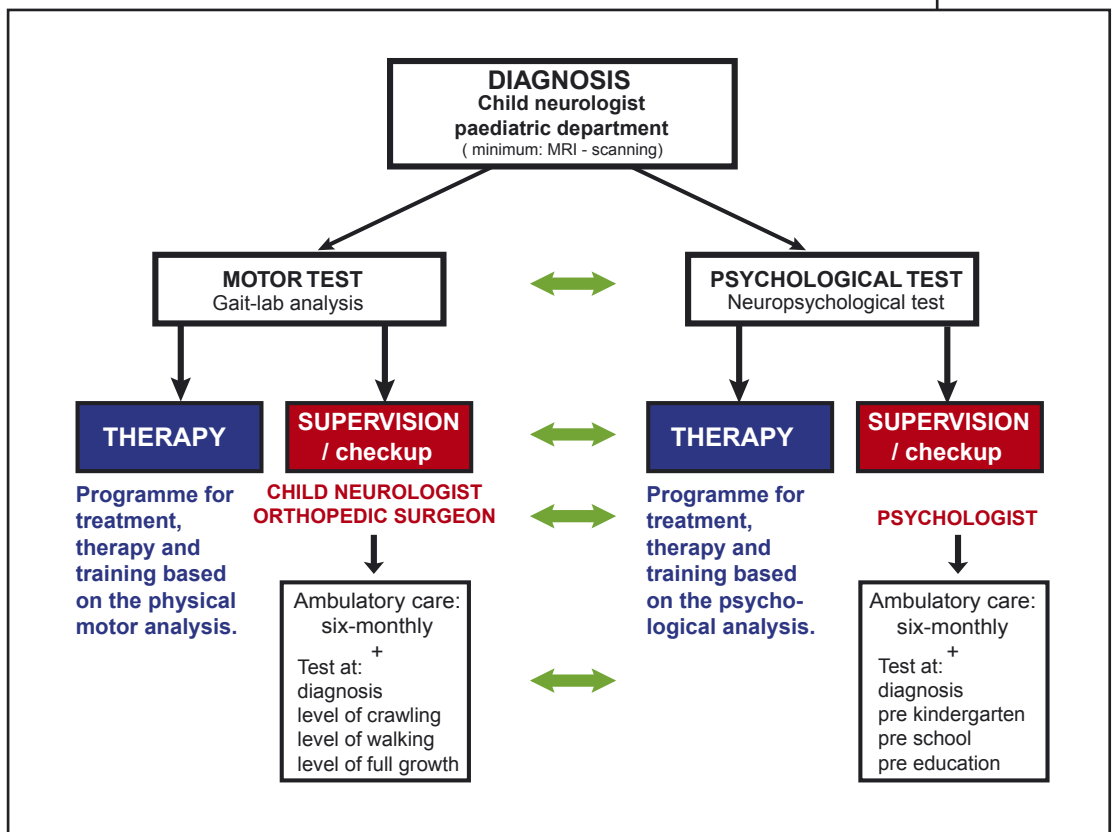


Diagram showing the strategy of treatment and therapy that The Danish Society for Cerebral Palsy will work for in the future. The two „columns« - the motor and the psychological one - must continuously communicate. Here symbolized by the green double-arrows. This plan is considered a minimum, but as a beginning it is vital that this model becomes widely accepted as the automated general treatment options for new diagnosed children with cerebral palsy.

A new definition could be termed as follows:

*“Cerebral palsy signifies a complex syndrome caused by a brain damage predominantly occurring prior to birth during early development of the brain.*

*The brain damage affects the basic management of sensory processing and involves reduced control in relation to sensory input-output systems. The symptoms are seen as individual disabilities within motor and cognitive functions”*

A modified and broadened definition will eventually result in a fundamental renewal of strategy and concept of treatment. New CP is based on the paradigm shift stating that: *the basic phenotype of cerebral palsy is perceptual impairment.*

However the nature of cerebral palsy makes it evident that the diagnosis must be made from the physical-motor symptoms because they manifest themselves early and distinct compared to the cognitive symptoms. Moreover the diagnosis should be made as early as possible – preferably by upgrading the paediatric departments to make use of the GM-diagnostic tool (*General Movements – also known as the Prechtl-method*) [39,40, 41,42] and certainly MR-imaging of some kind should be compulsory.

The concept of New CP suggests that a psychological appraisal should be made as soon as it is viable after the diagnosis, because it is of vital importance to introduce adequate training of the cognitive functions as early as possible.

Subsequently the developing of a treatment and therapy programme must establish an overview of the child’s profile of function. The programme must be directed at two equal and fully integrated courses – two strategies of equal importance: the motor one and the cognitive one.

The present diagnostic practice implies an increased risk of over focusing on the motor disorder. Consequently an artificial barrier is created between motor and cognitive function. The structured treatment programme should as an overall purpose elevate and improve functions, social interactions and quality of life for individuals with cerebral palsy. Thus focus should involve both motor function and cognition.

The interplay of the different areas of function in the child should carefully be assessed and evaluated in order to determine the right treatment and therapy and in so doing plan the best approach.

This presupposes interdisciplinary diagnostics and practice as well as intersectorial cooperation. ■

## Epilogue

For cerebral palsy - as a diagnosis - it is of vital importance to introduce adjustment – widening - and clarification.

As things are for now the diagnosis has lost its value and meaning. It has become so narrow and simplified - focusing unambiguously on the motor disorder and the outer symptoms – that the brain damage, which in fact causes the syndrome, is almost forgotten – or even worse misinterpreted as a brain damage that only involves motor disorder. This goes against and neglects present knowledge, established facts and the very nature of a brain damage.

If cerebral palsy is going to survive as a diagnosis and regain respect as a term, which is well described, well defined, well delimited, the perceptual-cognitive-motor-continuum must be recognized.

For people with cerebral palsy it is of fundamental impact that the perceptual – cognitive element is made integral – both in the definition and in the characterization – but most important of all: in the treatment and the overall therapy programme.

The general practise of today means that a very essential part - very likely the most important one in relation to a complete life – is neglected and ignored. This is neither reasonable nor fair towards the ones already diagnosed with cerebral palsy or the children who are going to be diagnosed in the future.

As evidence and indications so coherently suggest that specific cognitive deficits not only are associated handicaps but constitute a fundamental factor for understanding the entity of the syndrome cerebral palsy and the treatment necessary - only one right and unimpeachable solution seems to exist:

a new definition

a new characterization

and a new strategy

**= a paradigm shift to “NEW CP”.**



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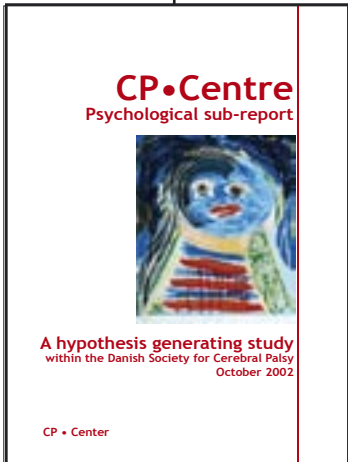
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## Exhibit A

Summary of:  
**Psychological sub-report (Oct. 2002) from:  
CP•Centre – a hypothesis generating study  
within The Danish Society for Cerebral Palsy.**



**Pia Kuhlman**, MPsy., clinical psychologist – CP•Centre, The Danish Society for Cerebral Palsy, Flintholm Allé 8, DK2000 Frederiksberg, Denmark.

### Process:

As part of the analysis and assessment programme of the CP•Centre, which consisted of a physical, a psychological and a social appraisal, it was decided to have all included patients tested with the WAIS-R neuropsychological test battery.

In addition to a thorough clinical interview the WAIS-R test battery was chosen, as this battery is an integral part of the standard neuropsychological appraisal.

In this study the test battery has been used to indicate if specific affected cognitive functions could be demonstrated as the brain damage per se was evident due to the diagnosis of cerebral palsy.

The results from the WAIS-R test battery was analysed quantitatively but was interpreted qualitatively in relation to each individual patient. The analysed data show tendencies of a similar comparable pattern of cognitive deficits in the majority of the patients.

In general brain damages indicate reduced motor speed, impaired short-term memory as well as attention and concentration difficulties. This will have an influence on the general learning abilities. Furthermore in the present material perception and structuring impairments were found.

### Conclusion

The results suggest that the motor speed in the majority of the patients is affected. The data show general impairment of perception, attention, structuring and concentration. Moreover hand-eye coordination is compromised. This could imply that some of the subtests were not accomplished in an adequate way.

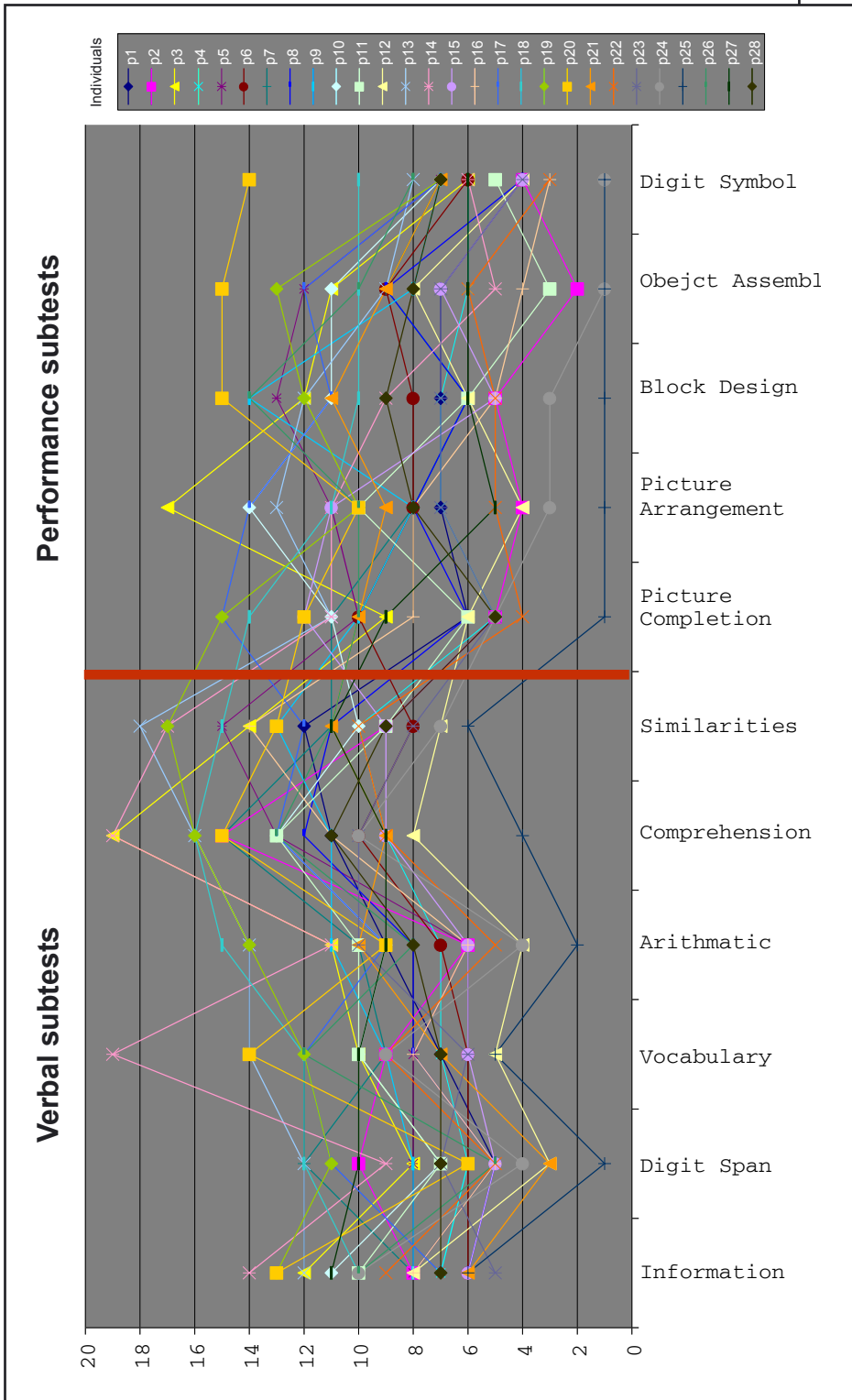
The tendencies in this study should be made an object for further research in as much as the material in the present study was selected. A more specific individual study on a bigger population is recommended with the purpose of showing that the results in a sufficient manner could prove evident in an unselected cerebral palsy population.

The tendencies are after all noteworthy. On the basis of the present material it is recommendable that individuals with cerebral palsy are psychological appraised early in life as it is of vital importance that adequate cognitive training is introduced as early as possible.

Moreover the necessary resources must be made available within school and education to compensate the specific cognitive impairments.

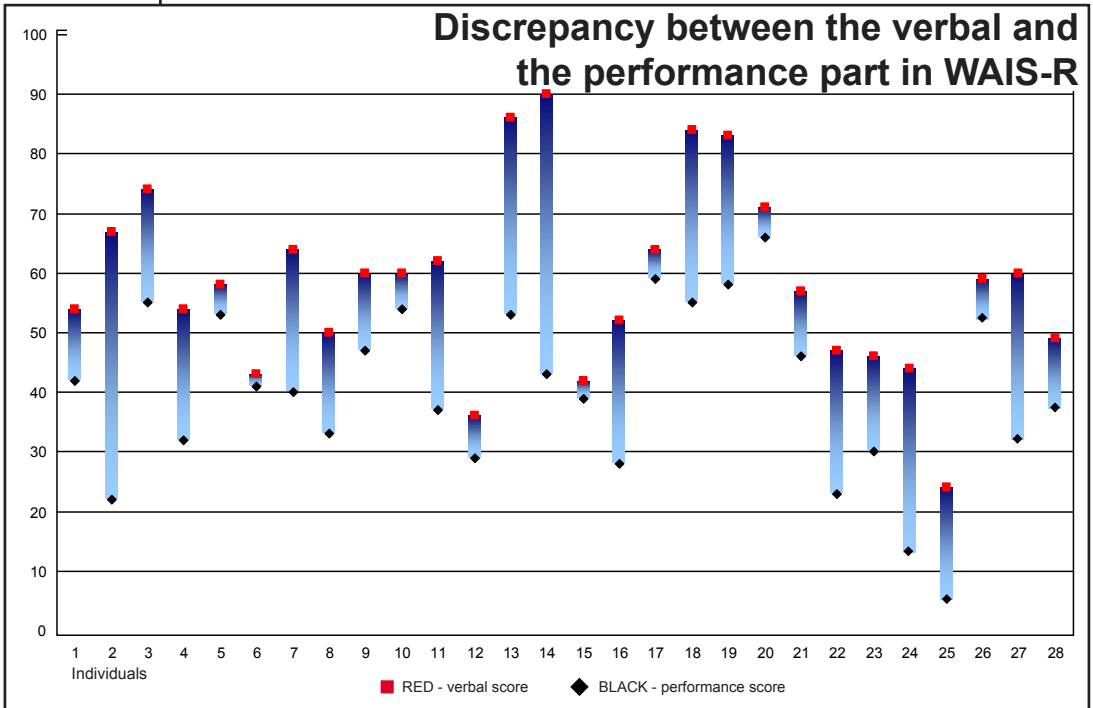
IQ calculation as such is inadequate as instrument of appraisal in cerebral palsied individuals. ■

**Exhibit A-1:**



This figure shows that the subtests sensitive to brain damage are affected in this material. Moreover the subtests related to perception manifest a lowered level.

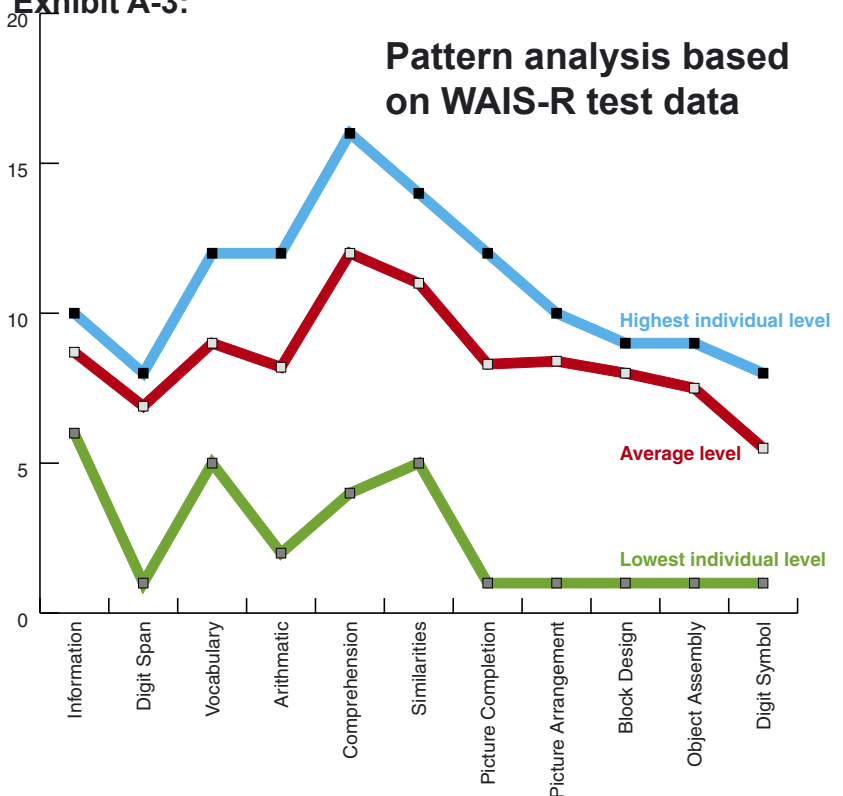
**Exhibit A-2:**



This figure shows the discrepancy between the verbal-scaled-score and the performance-scaled-score.

In 71,4 % of the tested individuals the discrepancy is above 11.

**Exhibit A-3:**



The test results show a distinct pattern in all of the tested persons – irrespective of individual level.

A closer interpretation of the patterns suggests the presence of a perceptual brain damage.

## Exhibit A-4:

### Material – data:

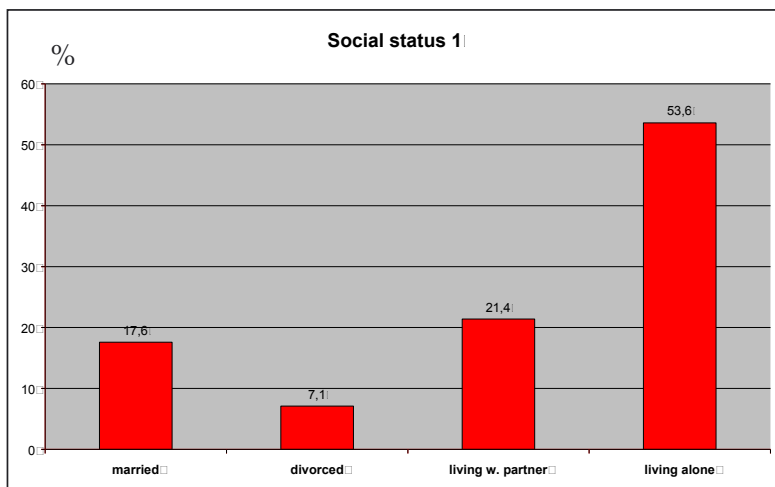
#### Gender:

28 individuals with verified cerebral palsy: 18 females (60,7%) and 10 males (39,3%).

#### Age:

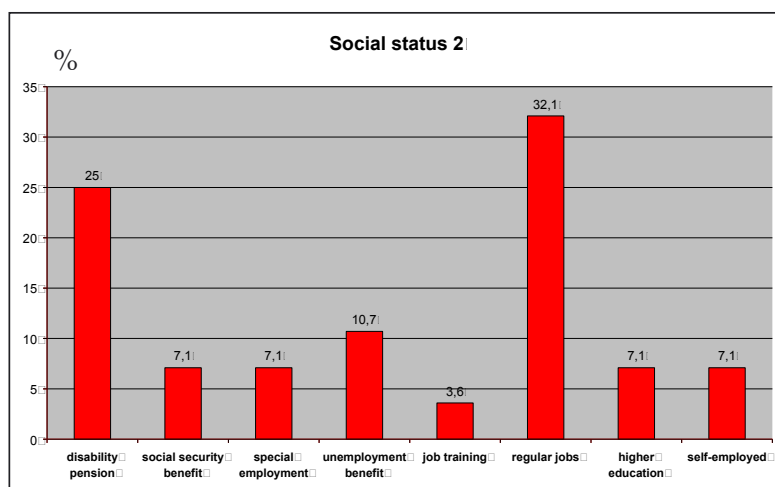
Average age: 32,21 years, (17 – 48 y).

### **Social status:**



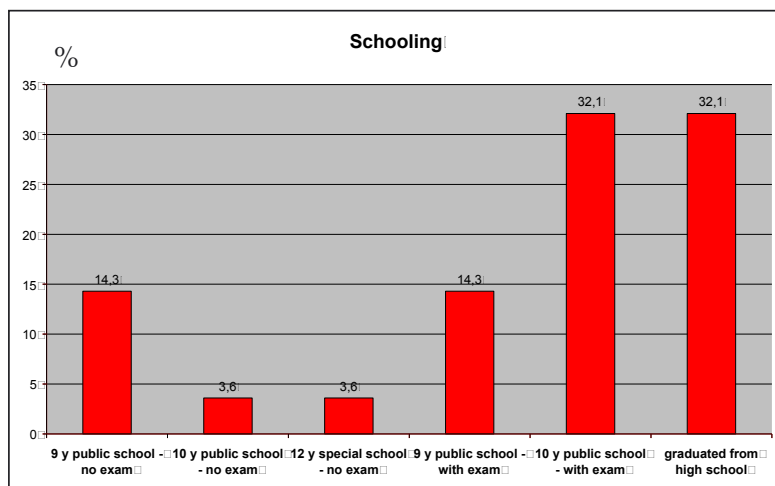
5 married (17,6%), 2 divorced (7,1%), 6 with partner (21,4%) and 15 alone (53,6%).

10 with children (32,1%): 6 with one child, 3 with 2 children and 1 with 3 children.



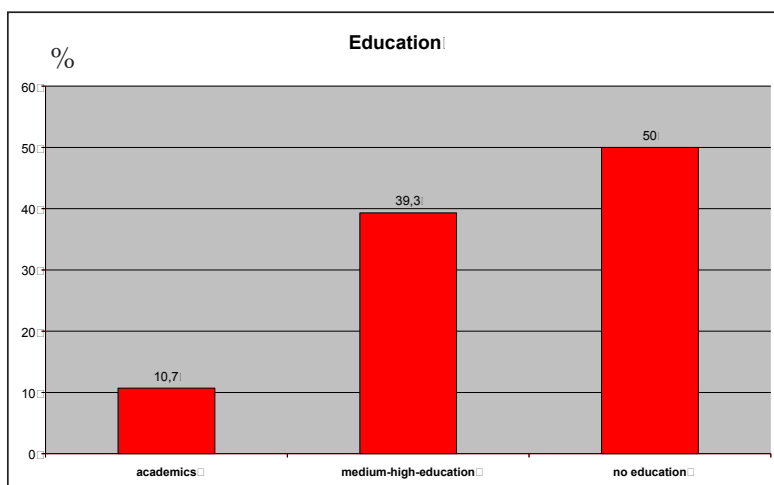
7 on disability pension (25%), 2 on social security benefits (7,1%), 2 in special employment (7,1%), 3 on unemployment benefit (10,7%), 1 in job training (3,6%), 9 in regular jobs (32,1%), 2 at higher education (7,1%) and 2 was self-employed (7,1%).

## Schooling and exams:



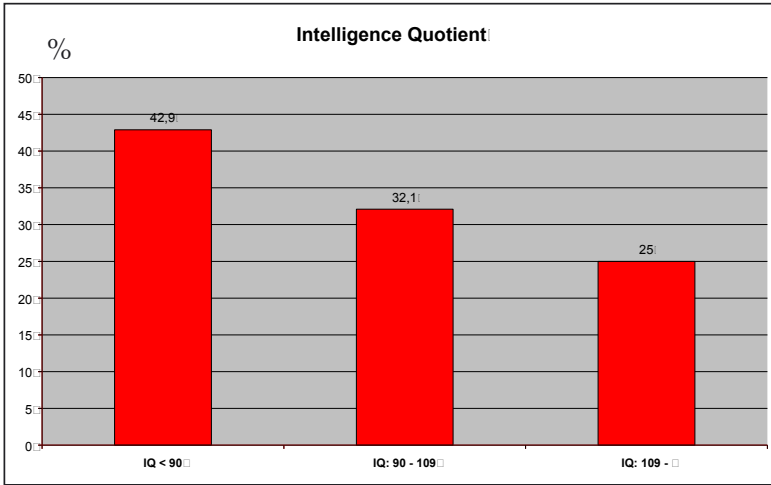
- 4 (14,3%) 9 years of public school – without exams
- 1 (3,6%) 10 years of public school – without exams
- 1 (3,6%) 12 years of special school – without exams
- 4 (14,3%) 9 years of public school – with exams
- 9 (32,1%) 10 years of public school – with exams
- 9 (32,1%) graduated from high school

## Educations:



- 3 (10,7%) academics (university 6-7 years)
- 11 (39,3%) medium-high-education (technical college 3 –4 years)
- 14 (50%) no education

## IQ:

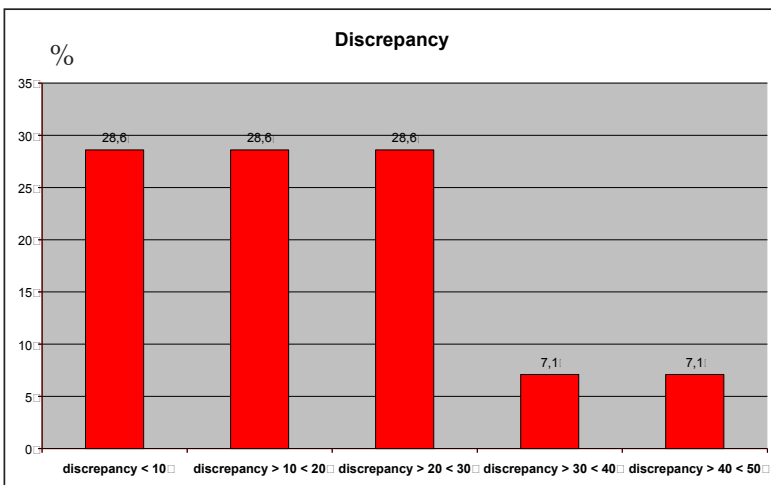


12 (42,9%) IQ < 90

9 (32,1%) IQ = 90 – 109

7 (25%) IQ = 109 – , whereas 4 with an IQ > 120

## Discrepancy:



## Exhibit B

The following two pages contain a summary of the case presented by Dr. Abigail Golomb at the 5. International Congress on Cerebral Palsy in Slovenia, June 2001.

Ariel was diagnosed as suffering from CP from birth. There were no problems during the pregnancy or birth. It was noted that he had „something wrong“ with his right side, mainly right leg.

His parents were both successful working professionals, the mother a lawyer and the father a businessman. They had a healthy daughter, aged 4 when Ariel was born. The father had a sister he was very close to; the mother had no siblings. All 4 grandparents were alive when Ariel was born, and had been involved with the sister but had not been permanent caretakers. The family had daily help but not live-in help.

This had been a happy marriage and the compromises necessary for both of them to work and yet remain involved with the daughter had been easily made. In fact, they had had no real problems until Ariel was born, being used to working hard for what they wanted – and then achieving it.

Their attitude towards Ariel’s problems paralleled this. There was no immediate depression or shock, but a major involvement in finding the best doctors, reading up about CP, and even seeking short term psychological advice about how to explain things to their daughter. In short, they coped. They did not „shop around“ too much. They found that the medical treatment (mainly tendon operations and physiotherapy) in the hospital they were referred to was considered on a high level; but did go to the United States for 3 months to see if there was a better operation, and kept up contact with the hospital and doctors there as well. After that they concentrated on leading as normal a life as possible, and on giving Ariel a normal life.

Ariel could walk, though slowly and awkwardly. They resisted any mechanical aid in walking, feeling he was more independent and more normal this way. His fine motor functions were also affected, and by age 4 it was clear there were some coordination problems. But the local kindergarten and his physiotherapist felt they could deal with this and he continued in a normal setting. It was assumed that Ariel had only physical problems, affecting his gross and fine motor skills, and nothing else. There was never any psychological assessment. The parents felt that they and the children were fine emotionally – they were all coping and happy and the words depression, anger, despair, worry about the future, etc. – were not part of their language.


Thus, at age 5, while in kindergarten and before entering school, the formula would read like this:

His overall adaptation, as considered by the family – was just fine. At this stage, as far as one can reconstruct, Ariel was assumed to have achieved all the necessary developmental landmarks appropriate to his age. Ariel had some motor impairment, assessed by the social security standards in Israel as 15%. At the time it was assumed there was no neurological impairment and Ariel was assessed as normal for age cognitively.

As will be seen with many children, this was just an assessment by his parents and kindergarten staff. No formal assessment was done. The family, in their own view, were doing just fine.

In our professional view they had skipped a significant and important stage – the mourning stage.

At age 6 Ariel entered a regular school. It soon became apparent that he had some learning disabilities that could not be explained by his difficulties in writing. The school was very interested in mainstreaming him and giving him every help possible. So someone in class wrote down homework for him, and one of his parents regularly did homework with him, doing part of the writing for him. Later he progressed to a computer.



All this help masked his learning disabilities, which began to show themselves more as acting out and behaviour disorder. He would lose patience and get angry, blaming his difficulties on his motor problems.

Socially, Ariel had had good relationships in kindergarten, but in school things were a bit more difficult.

His parents had all the latest computer games, and often kids came over to play with them – and him – but he couldn't keep up to their speed or join in any other games. Also, we later found that his learning disabilities affected his concentration and mathematical skills, and some of the games depended on this.

The real crisis came in the third grade. At that time, his class was supposed to move to the third floor, with no lift. This was a sign of leaving the „little ones“ on the lower floors. They should have moved during the second grade, but Ariel's disability, and the desire of the school to make him feel normal, made them postpone the move. But by the third grade, the other children were beginning to get angry at this. So the class moved, and Ariel in effect was limited to the classroom. By the time he walked down 3 flights of stairs he had to go up again, so he just stayed in the classroom and didn't join the other children during the breaks.

For the first time, his parents considered mechanical aids – an electric chair for the stairs, for instance. But by then Ariel saw this as a stigma, and refused to consider it. They were used to going by his wishes, and agreed to his refusal – seeing it as a good sign of being like everyone else.

This third grade was a traumatic year, as the learning problems became more and more clear, the lack of social skills could not be attributed solely to his motor problems, and for the first time the parents had to face the fact that there was nothing they could do that would change things. In fact, this was the first time they began mourning. It was a difficult process, but they finally realized that they had a son with problems that couldn't be made to go away, and just doing everything normally was no solution. The social success of his sister was an added problem. They almost suggested to her that she refrain from bringing friends home, so as not to irritate him. When they realized what they had almost done – they finally suggested a big change in the whole program for Ariel.

Ultimately, he was put in a special school for children with CP, where he was top of the heap – he had a lot of abilities some of the other children didn't have. He also went through anger and mourning, and refused any educational help until he had come to terms with the fact that he indeed had a disability. I am sure that if the parents had not undergone their own mourning, and had not realised the full effect of the disability, they would not have been able to help Ariel and would probably have cued him that mourning and depression were unacceptable.

By the age of 13 Ariel had stopped talking about his future brilliant army career and was concentrating on music, taking special education for his math and reading problems, had accepted the special conditions the ministry of education allows for children with learning disabilities (a longer time for taking exams, or doing them orally rather than in writing). He openly expressed his jealousy of his sister – while loving to hear tales of her successes. His parents took him to Europe for the first time „just for fun« and not to see a consultant.

When Ariel was 17 his parents asked to come in for a short followup, without Ariel, just to tell me how difficult it had been for them to accept weakness, to accept there were some things that time, money and effort couldn't fix – and how they realized that until they accepted this, they had been pressuring Ariel to be successful in their terms, and not in his own. ■

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As evidence and indications so coherently suggest that specific cognitive deficits not only are associated handicaps but constitute a fundamental factor for understanding the entity of the syndrome cerebral palsy and the treatment necessary - only one right and unimpeachable solution seems to exist:

a new definition

a new characterization

and a new strategy

= a paradigm shift to “NEW CP”

