

## РЕКОМЕНДАЦИИ ПО РЕАБИЛИТАЦИИ ДЕТЕЙ С ДЦП. ЧАСТЬ II

<sup>1</sup> Детская клиника Bambino Gesù, Рим, Италия

<sup>2</sup> Spedali Civili, Университет в Брешиа, Италия

Enrico Castelli<sup>1</sup>, Elisa Fazzi<sup>2</sup>

## RECOMMENDATIONS FOR THE REHABILITATION OF CHILDREN WITH CEREBRAL PALSY. PART II

<sup>1</sup> Bambino Gesù Children's Hospital, Rome, Italy

<sup>2</sup> Spedali Civili, University of Brescia, Italy

On behalf of the Italian Society of Child and Adolescent Neuropsychiatry (SINPIA) — Italian Society of Physical Medicine and Rehabilitation (SIMFER) Intersociety Commission.

### Резюме

Рекомендации предназначены для специалистов с высшим медицинским образованием, отвечающих за разработку индивидуальных программ реабилитации (детских нейропсихиатров и психиатров), терапевтов и прочих медицинских специалистов, занимающихся оценкой состояния и лечением детей с ДЦП (ортопеды, педиатры, офтальмологи, неврологи и т.д.), психологов, социальных работников, технических специалистов реабилитационной группы межпрофессионального взаимодействия (техник-ортопед, ортоптист, специалист по визуальной реабилитации, медсестры и т.д.), семей, имеющих детей с ДЦП, а также учителей и работников образования, работающих с больными детьми как в школе, так и за ее пределами.

Рекомендации состоят из пяти разделов. Во введении дано четкое определение рассматриваемого заболевания и подчеркнута важность Рекомендаций с клинической и организационной точки зрения; в нем также содержится обязательство по разработке таких Рекомендаций двумя научными сообществами, представлены список членов Комиссии, используемые методы работы, адресаты Рекомендаций, области применения, методы мониторинга и обновления. За введением следует текст Рекомендаций, состоящих из трех следующих разделов: определение функционального профиля пациента с учетом двигательных расстройств и прочих нарушений; цели проведения самообучающих процедур (с учетом возраста паци-

### Abstract

The Recommendations are aimed at the specialist medical doctors responsible for individual rehabilitation plans (child neuropsychiatrists and psychiatrists), at therapists, and at the other medical specialists involved in the evaluation and treatment of children with CP (orthopaedists, paediatricians, ophthalmologists, neurologists, etc.), as well as psychologists, social workers, the technical members of the interprofessional rehabilitation team (orthotist, orthoptist, visual rehabilitation therapist, nurses, etc.), the families of children with CP, and the teachers and educators involved in managing affected children, both at school and outside school.

The Recommendations are structured in five parts. The *introduction* provides a clear definition of the disease in question and outlines the importance of the Recommendations from a clinical and organizational perspective; it contains the mandate to draw them up, conferred on the two scientific societies involved, and it also lists the members of the Commission, the working methods followed, the addressees of the Recommendations, the areas of application, and the monitoring and updating methods. The introduction is followed by the *Recommendations* themselves, which are organized in three sections: the definition of the patient's functional profile, according to motor and non-motor axes that describe his/her disability; the fields (aims) of the re-education intervention (differentiated by patient age); and finally the operating

ента) и, наконец, оперативные вмешательства, которые должны проводиться в ходе проведения самообучающих процедур. В свете последних исследований добавили раздел Подробный анализ, для того чтобы дать определение и уточнить некоторые вопросы и термины, касающиеся лечения детей, страдающих ДЦП (например, нарушение зрения при ДЦП, качество жизни, боль и инновационные реабилитационные процедуры). Наконец, за обновленным списком литературы следует приложение, содержащее рекомендации относительно содержания программы по самообучению для различных возрастных групп.

**Ключевые слова:** реабилитация, межпрофессиональный, нейропсихиатр, обучение, применение

methods to be used in the re-education intervention. In the light of recent research, a section of *in-depth analyses* has been added with the aim of defining and clarifying certain topics and terms relevant to the care of children affected by CP, such as cerebral visual impairment, quality of life, pain and innovative rehabilitation procedures. Finally, the updated *bibliography section* is followed by an *appendix* containing suggestions on the content of the re-education plan, differentiated by age group.

**Key words:** rehabilitation, interprofessional, neuropsychiatrists, education, application

## JUSTIFIED FIELDS OF INTERVENTION DIFFERENTIATED BY AGE

### Age groups

In order to allow a rational interpretation of the evolution of the main functions, on the basis of what is described within the single justified fields of intervention, the following age groups (in line with the structure of the ICF-CY) have been established: 0–2 years, 3–5 years, 6–8 years, 9–12 years, 13–18 years and over. When a patient's functional diagnostic profile is considered in relation to his age, it assumes a more specific significance and can be updated constantly so that it is always current.

### Justified fields of intervention

The justified fields of intervention are determined on the basis of the data relating to the patient's profile, and are related to:

- 1) The architecture of the main functions (activities/abilities) on which to intervene for therapeutic purposes (the focus of the re-education plan);
- 2) The types of these main functions, which can fall within the following areas: autonomic control, personal autonomy, locomotion, *manipulation and praxis*, sensation/perception and gnosis, cognition, communication, relationships;
- 3) The compatibility of the therapeutic targets with the activities/abilities and the levels of participation appropriate to the age group considered;
- 4) The priority functional activities/abilities and the levels of participation that the child with
- 5) CP should, considering his specific age range, succeed in attaining; in other words the developmental stages (windows for intervention/critical periods). In this sense, the priority functional activities/abilities do not respect a predetermined hierarchical order (milestones), but change depending on the child's age group. For example, walking is an important goal between the ages of 0 and 2 years and between the ages of 3 and 5 years and, in certain situations, can continue to be so between 6 and 8 years of age, but after this time it ceases to be an important goal, except in exceptional, justified circumstances. Conversely, the achievement of adequate autonomy in the sitting position becomes very important in children who use a manual or electronic wheelchair, an aid that, moreover, can be proposed for patients as young as 3 to 5 years of age, if they have a negative prognosis for walking;
- 6) Continuation of the re-education treatment cannot be considered justified if, after a reasonable period of time has elapsed, there has been no significant change;
- 7) Continuation of the re-education treatment is also unjustified if the patient proves unable to learn and acquire the induced modifications of the function in question (which results in a continuous demand for so-called maintenance therapy). Upon completion of rehabilitation treatments whose aim is the patient's acquisition of optimal functional skills, there nevertheless remains

the need to contain disorders, due to non-use, of the locomotor and respiratory systems and to prevent/treat pain. This intervention, which falls within the care sphere, demands periodic medical checks (at least annual), serving to monitor secondary degenerative disorders and identify new therapeutic possibilities made possible by advances in neuroscience and technologies.

- 7) The assessment of the patient must take into account not only the single functional area involved, but also its relationship with the other areas, so as to be able to define the overall level of development attained and the impact, on this, of the area in question. In seeking to characterize the elements comprising the different functional areas, it is important to provide not just a mere description of the phenomenon (it is present/it is not present/it is partially present/it is emerging), but also to state whether and in what way the child implements adaptive, compensatory or additional strategies, not least because these can serve as a crucial guide for the proposed therapy.

### Operating method

The «taking on» or «taking charge» of a patient should be understood as a technical intervention that, as broad and appropriate as possible, should accompany him throughout his life, its aim being to favour adaptive, interactive and reciprocal development that can range from education of the disabled person himself to education of others about disability. It should allow the identification and organization of appropriate actions to ensure maximum participation in social, economic and cultural life, in relation to the development of abilities, both achieved and potential, and the age and expectations of the individual. The resources for the «taking on» process lie in networks of services, family, friends, and volunteers. It is desirable to avoid delays in the taking on of a patient.

To be as effective as possible, the rehabilitation intervention should be:

- timely
- intensive
- ongoing
- family-centred:

The rehabilitation plan is formulated in relation to each single justified area of intervention through a procedure (rehabilitation method) that involves the following steps:

- Functional assessment (functional diagnosis);
- Functional prognosis, or prediction of possible modifications, also related to intervention on contextual factors;
- Construction of the rehabilitation plan;
- Definition of the treatment programme;
- Reaching of the therapeutic agreement (therapeutic contract);
- Multidisciplinary approach and teamwork.

1. Functional assessment and functional diagnosis of the patient through a *direct observation* and an observation guided by the use of *protocols* built around the particular characteristics of the development of a child with CP. In the assessment of the child, alongside the descriptive tools specific to each service, standardized instruments or instrumental methods will be used, whenever possible, in order to make the assessment itself more objective, measurable and comparable over time and between observers. This will be followed by the declaration of the functional prognosis, namely the predictors, positive and negative, related to the functional area considered, on which is based the judgement on the possibility of achieving the expected final change, i.e. the objective of the re-education plan. These predictors must take into account the multiplicity of the functional areas involved and their interactions (the «globality» of the re-education plan as opposed to the «specificity» of the re-education interventions performed by each professional).

2. The re-education plan itself should consist of concrete activities/abilities pursuing realistic goals. The re-education plan cannot therefore be laid down on a predetermined basis (application of a method as a preconceived universal formula), but must be adapted to the needs, problems and resources of the particular child with CP and of this family, and, accordingly, must be regularly assessed and reviewed [16, 17].

It is recommended to use the ICF-CY as a classification tool both when planning individualized interventions and treatments and as an outcome benchmark for the interventions themselves.

It is appropriate to declare the therapeutic instruments that it is intended to use in order to achieve the short-term goals and the indicators that will be used to measure the result obtained. The instruments must be strictly pertinent to the justified area of intervention considered and must have been validated internationally, adopted by many public or private

centers simultaneously, or published in relevant accredited journals.

Attention should be paid to the results of clinical trials that are testing the effectiveness of new proposals in re-education, such as action observation therapy, constraint-induced movement therapy and robotic rehabilitation, in order to grasp their full innovative potential.

3. The drawing up, together with the family and the child himself (compatibly with his age and cognitive level), of the therapeutic agreement related to the re-education plan, i.e. of the agreement on what it is undertaken to obtain through the re-education treatment, should actively involve the family, albeit with due distinction of roles. Generally, the therapeutic agreement should be renewed once a year. Consent to the treatment from the family and, when possible, from the child himself is therefore an essential prerequisite to the treatment.
4. The family constitutes an invaluable resource. It is therefore always necessary to encourage and support a positive and proactive attitude, on the part of the family, towards the child with CP and also towards the service responsible for his care. It is necessary to foster, in the parents, an awareness of their child's real conditions (diagnosis), highlighting the role that they may play in the recovery processes (prognosis) and in promoting their child's self-determination (ability to make decisions), self-sufficiency (knowing what to do) and autonomy (being able to do things by himself). The family should, through the «taking charge», be offered maximum support and if necessary adequate «counselling».
5. Parents should be given continuous, coherent and comprehensible information on the therapeutic goals to be pursued (and the relative time limits) and on the means through which they will be pursued; this information should include the recovery prospects (potential and limitations). It is wrong to expect parents to fulfil the role of therapists, delegating the rehabilitation intervention to them (as this amounts to obliging them to shoulder responsibilities that are not their own), but it is equally wrong for parents to hand over the rehabilitation work entirely to therapists. Rather it is necessary to identify, together with the parents, a series of situations in which the child with CP can, in his everyday life, have experiences that are useful and coherent with the recovery process that is under way

(concordance). In this way the child will be able to apply more generally the things he has learned in specific therapy situations. A similar kind of involvement (active and collaborative) on the part of educational establishments and schools is also to be encouraged. If other relatives play a key role in the child's education (supporting the family), they should be involved in the treatment processes directly and not just through the parents.

6. The implementation of the re-education plan demands a multidisciplinary approach that includes the intervention of the different professionals who together contribute to its realization (child neuropsychiatrist, psychiatrist, psychologist, therapists, orthotist, etc.). There should also be a network of professionals who specialise in the problems associated with CP (orthopaedist, ophthalmologist, dietician, etc.) and can complement the specific assessments carried out by the professionals who normally look after the child. Use of the ICF-CY, as a communication tool facilitating this multidisciplinary, is recommended.
7. The treatment program must be based on the evaluation of intermediate changes, or the achievement of short- and medium-term targets, having first established the time within which it is deemed possible to obtain the change that is being sought. The methodology applied in verifying the progress made by the child, in relation to therapeutic intervention implemented, features among the criteria for accreditation of the rehabilitation center.

Since the instruments used in this procedure are ones serving to verify the acquisition, by the patient, of performances that indicate achievement of the expected change (i.e. the intermediate and/or final change), the target we are trying to reach (i.e. the different levels of modification of the function in question) needs to be described in terms of its simplicity, observability, communicability and measurability, in other words, it is necessary to clearly state how the child was prior to the treatment and how he is immediately after it. To constitute a successful therapeutic outcome, the result obtained must represent an improvement and it must be stable over time, objective, measurable and reproducible.

The definition of the treatment program demands a positive and ongoing interactive relationship between the specialist physician and the therapists, respecting their specific areas of expertise and responsibility.



- It is recommended to use the ICF-CY as the reference classification tool for identifying expected outcomes in relation to the interventions themselves.
8. The re-education treatment, in all its various components, should be tailored to child's needs (in terms of motivation and learning) and circumstances (changeability of the function, critical periods, psychobiological stages, characteristics of the physical, social and cultural environment).
  9. If the family requests a second medical opinion, they should be helped to obtain one from competent centres within the national health system. Similarly, they should be given information on complementary or alternative treatments, together with the Service's opinion on the scientific value of the proposed treatment. Details of any discussions that take place, including questions raised and answers given, must always be recorded in the clinical notes and a copy of the same given to the family.
  10. When re-education treatment is indicated, there exist no alternative options. When it is used simply to encourage motor activity, there always exist alternative options (play, sport, aquatics, horse riding, etc.). When it is not serving any purpose, the ethical course of action is to discontinue it, so as not to generate unjustified hopes and subsequent deep disappointments. Aggressive rehabilitation is never justifiable and can in some cases be considered a form of child abuse.
  11. Families should be informed about the activities of disease organizations, but such associations must not be given information about the family unless the family explicitly requests this.
  12. School and social activities should be encouraged and supported, even though they have no strictly therapeutic value. Play and social participation are indeed aspects of the «taking charge» of the child, even though they are not part of the approach to his treatment. To encourage play in children affected by CP, it is advisable to look for opportunities to collaborate with social workers. In children of school age, close interaction with the field of sports medicine is desirable.
  13. The following information should be clearly set down in writing in the individual subject's clinical notes: the clinical diagnosis, the functional prognosis and the therapeutic aims and instruments used. With the parents' permission, it may be helpful, in relation to the treatment planning, to make periodic video recordings of the child's performances. The information contained in the clinical notes should be updated at least twice a year and at every clinical check-up, even if there have been no substantial changes. All the different professionals involved should document their therapeutic activity in the clinical notes. The child's own paediatrician should be kept adequately informed throughout.
  14. Every paediatric rehabilitation service should develop a system for monitoring users' (parents and patients') perceptions of the quality of the work done, in all its different components.
  15. The child neuropsychiatrist and the physiatrist are the medical specialists involved in the rehabilitation of CP, and their roles and expertise are partly separate and partly overlapping. A medical specialist is always in charge of the overall treatment plan, understood as the sum/integration of all the possible interventions/operators involved, developed taking into account two aspects: the diagnosis and prognosis of CP (see In-depth analyses).

The family must participate fully in the formulation of the treatment plan, so as to be able to share the decisions regarding its objectives and instruments. Parental involvement and support are always crucial factors in improving the child's acquisitions (transfer of knowledge and development of expertise) and in adapting the environment to his needs.

A therapist is in charge of the treatment plan and the therapeutic process, whose aim is to help the child develop new skills. Several professionals can be involved simultaneously in the same treatment plan (physiotherapist, neuropsychomotor therapist, speech therapist, orthotist, occupational therapist, psychiatric rehabilitation therapist, educator, psychologist).

It is the medical specialist's responsibility to avail himself of the professional expertise of therapists during the drawing up of the treatment plan, especially at the beginning (e.g. through a «prognostic evaluation»). Once the re-education treatment is under way, the periodic updating of the treatment plan must necessarily be done with the contribution of all the therapists involved. Certain manoeuvres (simple and of a repetitive nature) can be entrusted to the family under the responsibility of and direct monitoring by the therapists.
  16. The multidisciplinary team of rehabilitation professionals must be large enough to cope adequately with the case load, and must have enough time to apply the assessment tools (including the ICF-CY)

necessary to plan and verify the therapeutic interventions; this team must be integrated in a regional and national network of childhood rehabilitation services, and its members must comply with the principles of continuous medical education, participating in training events specifically dealing with CP.

17. As regards the duration of medical examinations, the following should be borne in mind: 90 minutes for a first examination and 60 minutes for a follow-up, provided it is carried out within six months of the previous one, otherwise it should again last 90 minutes. In addition, it is necessary to consider the time that needs to be set aside for team discussions of the treatment (at least 60 minutes three times per year) and for collegial specialist discussions (at least 30 minutes each). It is recommended that each child should have 2–3 follow-ups per year during the first six years of life and one/two per year subsequently.
18. Treatment sessions should last a minimum of 60 minutes; 45 minutes should be allowed for a clinical check. Considering the recommended average of four sessions per week, a single therapist may be assigned a maximum of 12–18 cases, including patients receiving active treatments and periodic checks. The therapist must not administer more than six treatments daily.
19. Parents should be able to attend the rehabilitation treatment sessions, unless it is temporarily indicated otherwise. Therapists should be able to have meetings with the parents, possibly both parents, even in the absence of the child. These meetings should be scheduled and take place at regular intervals, at least six monthly. It is important that such meetings be conducted, separately or with the entire team, by all the therapists involved in the child's care.
20. If the child is hospitalized due to intercurrent diseases (chronic patient in an acute phase), the intervention is limited to the needs expressed. The hospital rehabilitation service must intervene on the current disease (addressing aspects such as respiratory assistance, positioning of the bed, feeding, mobilisation, guided play, etc.). There needs to be a two-way exchange of information (on the child's habits, the family's expertise, etc.) between operators in the local services and the hospital staff in order to ensure adequate treatment during the hospital stay. Similarly, on the child's discharge, the hospital should facilitate the prompt resumption of the rehabilitation treatment provided by the local services.
21. For the re-education of gross and fine motor functions in children over eight years of age it is preferable to opt for a regime of cycles (intermittent, time-limited treatment) in order to reach the goals agreed with the family (the very concept of a cycle of therapy implies declaration of the objective being pursued). At this age, areas of therapeutic intervention other than motor ones may take priority.
22. Intensive inpatient treatment is justified for certain clinical conditions; as a rule it should not last longer than 4–6 weeks, and one/two cycles of treatment per year can be administered. The centers that carry out intensive treatments support the work of local services in relation to defined objectives and particular phases (functional surgery procedures and related treatment, injections of botulinum toxin, training in the use of innovative orthopaedic devices, prognostic evaluation of young children or patients with particularly complex forms, the use of special techniques or instruments, the testing of innovative drugs, etc.).
23. Home therapy is to be considered exceptional and is justified only when the child cannot be transported because of his clinical conditions. It is very difficult to create an adequate setting in the patient's home due to the unavailability of suitable spaces, aids and resources; furthermore, the teamwork has to be sacrificed and the therapist has less emotional support.
24. Re-education treatments are not normally carried out at school, but the operators from local services can visit the child's school to observe his behaviour among his peers and to interact with teachers.
25. With a view to application of the ICF-CY, it is necessary for each service to equip itself with rating scales, at least one for each of the main functions.

### Essential bibliography

1. International Classification of Functioning, Disability and Health: ICF. © World Health Organization 2001.
2. *Raghavendra P., Bornman J., Granlund M., Björck-Akesson E.* The World Health Organization's International Classification of Functioning, Disability and Health: implications for clinical and research practice in the field of augmentative and alternative communication. *Augment Altern Commun.* 2007;23:349–61.

3. *Rosenbaum P., Paneth N., Leviton A., Goldstein M., Bax M., Damiano D., Dan B., Jacobsson B.* A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl.* 2007;109:8–14. Erratum in: *Dev Med Child Neurol.* 2007;49:480.
4. *Bax M., Goldstein M., Rosenbaum P., Leviton A., Paneth N., Dan B., Jacobsson B., Damiano D.* Executive Committee for the Definition of Cerebral Palsy. Proposed definition and classification of cerebral palsy. *Dev Med Child Neurol.* 2005;47:571–6.
5. *Mutch L., Alberman E., Hagberg B., Kodama K., Perat M.V.* Cerebral palsy epidemiology: Where are we now and where are we going? *Dev Med Child Neurol.* 1992;34:547–51.
6. *Bax M.C.* Terminology and classification of cerebral palsy. *Dev Med Child Neurol.* 1964;6:295–7
7. Surveillance of Cerebral Palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Dev Med Child Neurol* 2000; 42: 816–824.
8. *Krageloh-Mann I., Horber B.* The role of resonance imaging in elucidating the pathogenesis of cerebral palsy: a systematic review. *Dev Med Child Neurol* 2007;49:144–51.
9. *Towsley K., Shevell M.I., Dagenais L., REPACQ Consortium.* Population-based study of neuroimaging findings in children with cerebral palsy. *European Journal of Paediatric Neurology* 2011;15:29–35.
10. *Ferrari A., Cioni G.* Le forme spastiche della paralisi cerebrale infantile: guida all' esplorazione delle funzioni adattive. Milan: Springer; 2005 (The Spastic Forms of Cerebral Palsy. A Guide to the Assessment of Adaptive Functions. Milan: Springer; 2009).
11. *Hagberg B., Hagberg G., Olow I.* The changing panorama of cerebral palsy in Sweden 1954–1970. I. Analysis of the general changes. *Acta Paediatr Scand* 1975, 64:187–192.
12. GIPCI Gruppo Italiano Paralisi Cerebrali Infantili (edited by E. Fedrizzi) La valutazione delle funzioni adattive nel bambino con paralisi cerebrale Milan: Franco Angeli editore; 2000.
13. *Stevenson R.D., Conaway M., Chumlea W.C., Rosenbaum P., Fung E.B., Henderson R.C., Worley G., Liptak G., O'Donnell M., Law M., Hanna S., King G., Hurley P., King S., Kertoy M. and Rosenbaum P.* Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health and Development* 2003; 29: 357–366.
14. *Law M., Hanna S., King G., Hurley P., King S., Kertoy M. and Rosenbaum P.* (Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health and Development* 2003; 29: 357–366.
15. *Larson J.S.* New directions in medical outcomes research: the view from Harvard, *Review of Policy Research* 2000; 17: 99–110.
16. *Novak I., McIntyre S., Morgan C., Campbell L., Dark L., Morton N., Stumbles E., Wilson S.A., Goldsmith S.* A systematic review of interventions for children with cerebral palsy: state of the evidence. *Dev Med Child Neurol* 2013; 55: 885–910.
17. *Novak I.* Evidence based diagnosis, health care and rehabilitation for children with cerebral palsy. *J of Child Neurology* 2014; 29 (8):1141–1156.

#### Авторы

<i>Энрико КАСТЕЛЛИ</i>	Руководитель педиатрической реабилитационной службы Детской больницы «Бамбино Джезу», Рим, Италия
<i>Элиза ФАЦЦИ</i>	Врач-педиатр педиатрической реабилитационной службы Детской больницы «Бамбино Джезу», Рим, Италия