

Management Guide for the Child With Cerebral Palsy *

Foreword

This is the third in a series of Guides developed by the Committee for the Care of the Handicapped Child of the American Academy of Orthopaedic Surgeons, the first having been a Guide for the Management of the Child Amputee and the second, Management of Patients With Myelomeningocele and Congenital Spinal Defects Guidelines for Care.

The purpose of this Guide, which is endorsed in principle by the American Academy of Cerebral Palsy, is to express minimal essential professional requirements for program improvement and new program development for the child with cerebral palsy. It must be realized that no absolute or arbitrary standards are possible. There are many differences in local and state methods of caring for the handicapped child, availability of facilities and personnel, individual philosophies of approach, and personal differences in the medical and social requirements of children with the same diagnosis. With this Guide as a foundation, leadership by interested orthopaedic surgeons and other medical and paramedical personnel, coordinated with planning and cooperation by state and local community, education, social and therapy services, can lead to fulfillment of the needs of children with cerebral palsy.

Committee for the Care of the Handicapped Child, 1966-1967

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I INTRODUCTION

During the past 20 years considerable emphasis has been placed on the care for the child with cerebral palsy. The American Academy for Cerebral Palsy, an organization composed of professional people with a common interest in the problems of children with cerebral palsy, was founded in 1947. During this period cerebral palsy clinics were established throughout the country and were supported by volunteer agencies and by state and federal sources. The agencies included the National Society for Crippled Children and Adults, United Cerebral Palsy, State Crippled Children's Programs, and the Children's Bureau.

Many articles and books have been written on the management of the child with cerebral palsy. The American Public Health Association pub-

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lished its first guide entitled Services for Children with Cerebral Palsy in 1955 and at about the same time, the New York City Department of Health published recommendations for Comprehensive Care of Children with Orthopaedic Handicaps which also emphasized cerebral palsy. These guides and standards are being reviewed and revised in view of the more recent experiences in classification, prognosis, therapy techniques, and programs of medical, paramedical, and community care.

Children with cerebral palsy have multiple handicaps. The common denominator is brain damage. The damage may be focal or diffuse, depending on the etiology, but it is present in all. The complex nature of cerebral palsy requires understanding of the immediate problem and anticipation of those obstacles that will develop as the child approaches school age, adolescence and maturity. Physicians who assume responsibility for management of these children should have special knowledge concerning all of the physical, social, educational and vocational aspects of the child's development that must be dealt with during his maturation.

In cerebral palsy the "team approach" is the foundation of treatment. Awareness of medical advances as well as of the social, vocational, educational and psychological aspects, and knowledge of planning agencies are essential. Satisfactory management of the child's physical problems alone is not sufficient. It is but one of the many aspects that must be considered in the habilitation which will enable him to care for himself and to take his place as a functioning member of his family and community.

It is the purpose of this guide to outline those recommendations of the American Academy of Orthopaedic Surgeons which represent an expression of basic requirements of medical, paramedical and community personnel, and their functioning together as a team in the development of a coordinated care concept for the child with cerebral palsy. It is hoped that these guidelines can serve as a basis for the further development of realistic programs, the structure of which depends upon local facilities, resources, and philosophy of medical care.

Although "Cerebral Palsy" has become the accepted designation for this group of children, "A Guide for the Management of Neuromuscular Disease" might be a more appropriate title. Such a guide would include other conditions of the neuro-motor-skeletal system with similar problems, such as muscular dystrophy, myelomeningocele, myesthenia gravis, etc.

II CLASSIFICATION

Cerebral palsy is a manifestation of non-progressive brain damage. We may choose any one of a number of classifications; for example, etiology, pathology or the clinical manifestation. It is essential that both the medical and paramedical members of the team make the kind of evaluation which will lead to good overall planning and which will allow them to give sound advice to the parents.

An accurate initial evaluation permits a realistic therapy program for bracing, physical therapy, and surgery. For example, auditory impairment and dental problems are commonly associated with athetosis whereas convulsions and sensory deficits are more frequently associated with spasticity. Surgical procedures are much more successful in the child with spasticity than in the child with athetosis, and thus particular care must be taken in clinical assessment and classification. An example of classification follows:

FIGURE 1

<i>Diagnosis</i>	<i>Area</i>	<i>Etiology</i>	<i>Motor</i>
A. Spastic	Cerebral cortex (pyramidal)	Vascular or traumatic (prematurity)	Development of flexion contractures
B. Athetoid	Basal ganglion (extrapyramidal)	Anoxia (Rh and ABO incompatibility)	Involuntary activity without flexion contractures
C. Ataxia	Cerebellum	Anoxia	Most apparent during walking
D. Rigidity	Diffuse	Encephalitis	"Pipestem rigidity"
E. Mixed	Mixed pyramidal and extrapyramidal	Vascular, e.g. Caesarian section	Ordinarily a combination of an athetosis and spasticity

III RECOMMENDED STANDARDS

These are guidelines for minimum standards for care of children with cerebral palsy. Each clinic or medical program should include these basic essentials and expand on them, depending on the type of individual program. It is not enough to accumulate a group of certified medical and paramedical specialists if they continue to function as individuals. The child and the family will need the combined support of the entire group which means they must *function* together as a *team*.

A. Location of Facility

The facility should include adequate space for examination and a place for the children to play while they wait. A separate recreational room may be provided where volunteers may work with the children. In large facilities recreational therapists are valuable.

The clinics should be held adjacent to or in the physical therapy department so that training devices such as parallel bars, steps, walkers, and the like are available for use during physical examination.

B. Medical and Paramedical Personnel

Although defined separately, all individuals concerned with the care of these children should function as a "Team" with close coordination in order to insure that the care is comprehensive and continuous.

1. The *Director* should be a Diplomate of his specialty. He should be *specially trained and have special experience* in the care of children with neuromuscular disease, in particular cerebral palsy. He should maintain a sympathetic relationship with the child and the family and he should be knowledgeable regarding the use of community resources.

2. *Medical Staff*: The team should include a pediatrician, orthopaedic surgeon, neurologist and, whenever possible, a physician trained in physical medicine. Consultants in ophthalmology, otology, audiology, dentistry, and speech pathology should be available to work closely with the therapy team. Examination by the neurologist, orthopaedist, pediatrician, psychiatrist, or other specialist, may be performed as a group. Generally a more thorough evaluation can be performed when these examinations are done separately. Since the major needs of the child may vary from time to time, various specialists may have to take a greater degree of responsibility during the therapy regimen. For example, it may be that the child should be seen every

three months by the neurologist because of seizures, and only every six months by the orthopaedic surgeon. Likewise it may be that the child should be seen much more frequently by the pediatrician than by other members of the team. Regardless of the special examinations being performed and the therapy responsibilities at any particular phase of treatment, regularly scheduled periodic *team conferences* are essential.

The ideal arrangement might be to have the clinics scheduled so that the child attends all clinics on the same day. Those children who present a particular problem might be detained for a late afternoon discussion or simply rescheduled.

3. *Physical and Occupational Therapists* are essential members of the group. They should be graduates of an accredited school of physical or occupational therapy and be registered by the state. It is preferred that the therapist have had at least six months of special training in neuromuscular disease.

4. *Psychologist*: A qualified psychologist should work closely with the therapy team, rather than solely in consultation. He should be specially trained and have had experience with brain damaged children. The psychologist will frequently be in a position to direct the family counseling, or to assist the Director or the designated counselor. This is another one of the particular values of the team conference approach, since in many instances the specific medical problem is small compared to the overall problem.

5. *Social Service*: The size of the clinic will determine the number of medical social workers required. If the clinic is large, several medical workers are needed. A director of the section should coordinate the efforts of the various case workers. A well qualified social worker can alert the physician to the home situation, so that a more sound decision regarding therapy regimen, school placement, clinic visits, etc., can be made than one based solely on the physical and medical needs of the child. This close relationship between the family and the therapy team and the paramedical liaison with the medical social worker, nurse, and psychologist, may determine the success or failure of the treatment program in all of its aspects.

6. *Nursing*: The nurse provides effective liaison between the members of the team since she works with both medical and paramedical personnel. Sufficient clerical assistance should be provided to relieve the nurse of routine administrative duties; e.g., taking the children to the examination rooms, removing shoes, running for records and x-rays. The role of the nurse is more effective when she is utilized in counseling and working with community nursing agencies. These services may be added to regular nursing duties if clerical tasks are eliminated from her responsibilities.

7. *Bracing*: This facility should be available and the orthotist should be certified by the American Board of Prosthetics and Orthotics. An orthotist should be present at all clinics. Close cooperation among the orthotist, the orthopaedic surgeon and the clinic director is essential. The parents should be present at the time the brace is being prescribed and delivered so that they understand its use and the reasons for prescription.

C. Referring Physician

Close liaison should be maintained with the child's family physician, not only in the early stages of diagnosis and recommendations, but also as the treatment progresses. The physician should be invited to attend and participate in the total discussion and when he cannot attend, a report of the discussion should be sent to him.

D. In addition to the initial comprehensive examination and evaluation with the appropriate recommendations, the following practices should be observed:

1. Periodic team *reevaluation* of the child's gains, including all medical and paramedical members of the team.
2. *Resetting of realistic goals* that will be reevaluated at a specific time interval, the scheduling of such meetings to depend upon the stage of treatment of the child and his accomplishments to date.
3. *Inclusion of the family* in all or part of the conferences so that they are aware of what is going on.

E. Records

Typed records should be maintained and properly coded so that at any time during the treatment of the child his status can be determined. Some clinics prefer to have each specialist's note written in a different color, i.e. orthopaedic examination in red, the pediatric in green, and the neurologic in blue, etc. Others prefer to have the specialist's note written on a separate different colored page. Whatever the method of record keeping, it is essential that there be a unit system of records so that all notes, therapy schedules, x-rays, laboratory results, photographs, and other information relating to the patient be accessible for immediate review by all members of the team. There should also be facilities for movies, tape recordings, and other diagnostic and evaluative procedures.

F. Efficient follow-up

Appointments should be arranged at times which are feasible for the patient and family so as to reduce the number of broken appointments. An administrative assistant should review the records before the child appears, so that if x-rays, laboratory work or brace work will be required, the appropriate individuals can be present at the clinic at the time of the child's visit. In addition, the administrative assistant should bring to the attention of the physicians the records of children who have failed to keep their appointments so that a determination can be made as to the best means of follow-up. If hospital admission is anticipated, as much preliminary work-up as possible should be performed on an out-patient basis to shorten the in-patient stay.

G. Statistical Records:

The annual statement should include the number of patients who have been seen, the number of visits, the number of treatments by type, the number of new patients, the number of staff meetings, etc. Review of these statistics will reveal problems that need further investigation and will result in improved educational research training and better patient care.

H. Parent Guidance

Perhaps the most important part of all the services is the inclusion of the family in a discussion of the therapy programs. A number of effective methods have been devised, among which are the individual as well as the group techniques of parent guidance. The plan of therapy, the rationale of the treatment program, realistic goals and methods of family participation should be openly discussed, since the understanding and the cooperation of the parents may determine the success or failure of the prescribed treatment. Free discussion by the parents, particularly in a group setting, often brings to light deep-seated anxieties and concern that must be understood by the clinic director and the therapy team.

IV SUMMARY

This guide presents the minimal standards which the American Academy of Orthopaedic Surgeons believes are essential in the management of the child with cerebral palsy. These children have multiple problems which will require many skilled individuals who in turn must function as a team. This is only made possible by the active group participation of all of the members of the team.

The cerebral palsy clinic itself presents a challenge in management. The children are often difficult to control and the parents are generally anxious about the examination and conference. Whatever can be done to relieve the family tension and to insure that the family, the team, and the patient are striving for a common goal will be beneficial to the child.

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