



Standards
of Care
& Outcome
Measures

*for Children With
Cerebral Palsy*

Developed By:
The Committee on Children With Disabilities
of Children With Medical Handicaps and Ohio Chapter,
American Academy of Pediatrics

Ohio Department of Health • Children with Medical Handicaps

Standards of Care for Children with Cerebral Palsy

Definition	A non-progressive condition caused by a central nervous system lesion affecting movement and posture. It may include associated disabilities with onset during the developmental period.
Goal	These standards are prepared to assure that children with cerebral palsy have the opportunity to achieve their maximum function throughout life.
Core Team	The primary care physician is the provider of routine medical care and the child's medical home. A referral to a CMH approved multidisciplinary team to maximize coordinated services is recommended. Communication shall occur between the team and the primary care physician to assure coordination of all necessary services. The team shall consist of the parents of the child with cerebral palsy or the person with cerebral palsy, developmental pediatrician or pediatric neurologist, primary care physician, clinical nurse specialist or nurse practitioner, orthopedist, physiatrist, physical therapist, occupational therapist, speech pathologist, dietitian and service coordinator. The managing physician shall be a pediatrician, orthopedist, child neurologist or pediatric physiatrist with knowledge and skills related to children with cerebral palsy.
Comprehensive Diagnostic Evaluation	The initial evaluation shall be complete and detailed. The following components and professionals are recommended for conducting this evaluation:
Components	Providers
Family history	Pediatrician (may delegate task of collecting data), nurse and social worker.
Medical history	Pediatrician as case coordinator. Child neurologist and physiatrist contribute.
Developmental history and evaluation, including at least psychological, nutritional, social, physical and behavioral assessments	Pediatrician, child neurologist, physiatrist, psychologist, nurse, social worker, occupational and physical therapists, dietitian, and educator.
Physical examination, including at least neurological, musculo-skeletal, dental and ophthalmological assessments.	Pediatrician as medical care coordinator with referral to pediatric neurologist, physiatrist, orthopaedist, ophthalmologist, medical geneticist, dentist.
Laboratory/radiology	Pediatric radiologist Appropriate facilities as needed.
Hearing	Audiologist with pediatric experience.
Vision	Pediatric ophthalmologist

Educational Evaluation	Educator, psychologist, school nurse (with education/experience related to care of children with cerebral palsy), physical therapist, occupational therapist, speech pathologist.
Communication/ language (may include use of augmentative speech devices)	Speech pathologist, audiologist, educator, psychologist.
Nutrition/feeding	Pediatrician, dietitian, registered nurse, occupational therapist, physical therapist, speech therapist.
Service Coordination	Masters degree social worker, Masters degree nurse.

Consulting team

A coordinated team shall have access to additional professionals such as a geneticist, dentist, gynecologist, ophthalmologist, orthotist, psychologist, urologist, sex educator, social worker, neurosurgeon, gastroenterologist and pulmonary specialist.

Minimum frequency of visits

The infant should visit the treatment team a minimum of every four months or as determined by the treatment plan.

Content of Periodic treatment plans

As the child with cerebral palsy grows and develops, additional needs become evident that may require other disciplines and strategies. The following elements are recommended by age group without specifying the diagnosis or therapeutic interventions to be used. The listing is cumulative. A child entering the program for the first time would receive all items indicated up through the actual age group, as part of the initial evaluation.

Age Group

Re-evaluation emphases/concerns

Birth through 2 years

Vision, hearing, cognitive and motor development, hip stability, nutrition, dental, language and psycho-social concerns.
Referral for appropriate community programs and services. Periodic public health nurse home visits may provide additional assessment information.

3 through 5

Evaluation for preschool and early primary grades. Encouragement of optimal development by promoting educational, social, and recreational interaction in the least restrictive environment. Attainment of ability to perform appropriate activities of daily living.

6 through 12 years

Urological evaluation, if indicated. Patient understanding of disability. Pre-vocational counseling.

13 through 21 years

Vocational counseling. Transition to independent living. Transition to self care coordination.

CMH Services:

Request for treatment services for children with cerebral palsy must be made by an appropriate CMH physician provider.

Cerebral Palsy Outcome Criteria

Outcomes

Process Measures

A. Quality Management

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| 1) The child's care for the cerebral palsy condition is managed by a pediatrician, orthopedist, child neurologist or pediatric physiatrist with knowledge and skills related to children with cerebral palsy, in association with a multidisciplinary team. | 1 a) Referral made to the team for evaluation as soon as condition is suspected or within the first two years of life.
b) Treatment plans jointly developed and implemented by the family/person with cerebral palsy, the managing physician, and team.
c) Family has access to appropriate providers.
d) Care coordination is provided by the managing physician in association with the team.
e) Complex diagnostic and surgical procedures restricted to major centers.
f) Documentation of long and short term outcomes of the treatment plan.
g) Family participates in the development of the treatment plan. |
| 2) Service coordination is provided at the team and/or local levels. | 2 a) The child has an identified local service coordinator and team service coordinator, where available.
b) Documentation of a comprehensive plan developed by the service coordinator(s) which addresses the medical, social, vocational, educational, nutritional and recreational needs of the child.
c) The comprehensive service plan is updated at least twice yearly.
d) The family has input into the comprehensive service plan and demonstrates an understanding of, and agreement with, the content of the plan. |
| 3) Appropriate pediatric care throughout childhood. | 3 a) Has an identified primary care physician.
b) Physical exams and routine well child care provided on a regular basis.
c) Immunizations are current.
d) Periodic monitoring for growth failure, delayed development and other problems.
e) Mutual communication between the specialty team and the primary care physician, regarding the child's plan of care, progress and special needs/problems.
f) Family demonstrates knowledge of child's routine health needs and treatment plan. |

- 4) Preparation for transition to adulthood is initiated at an age-appropriate level.
- 4 a) A transition plan is developed during the teenage years.
- b) The teen/young adult and family have input into the transition plan.
- c) Qualified adult health care providers are available to assume health care at the appropriate time.
- d) The teen/young adult demonstrates ability to self-direct care or obtain appropriate assistance.

B. Physiological

- 1) Maintains adequate nutritional status.
- 1 a) Documentation of annual nutrition assessment by the primary care physician or dietitian.
- b) Maintenance and documentation by the primary care physician or dietitian of appropriate weight for height (length) ratio, per National Center for Health Statistics (NCHS) growth grids.
- c) Documentation by primary care physician or dietitian of skin fold measurements.
- d) Family demonstrates knowledge of strategies for child to attain and maintain appropriate weight for height.
- 2) Dentition maintained in optimal condition.
- 2 a) Regular dental appointments with appropriate dental providers.
- b) Documentation of current dental management plan.
- c) Treatment of dental and periodontal disease, including hyperplasia.
- d) Evaluation/treatment of malocclusions at appropriate intervals.
- e) Family demonstrates knowledge of appropriate oral hygiene techniques.
- f) Regular monitoring of dental and facial growth and development.
- 3) Child attains and maintains optimal neurological function.
- 3 a) Child has optimal seizure control, while maintaining function.
- b) Parent recognizes the signs and symptoms of changes related to neurological status and demonstrates knowledge of appropriate actions to take.
- c) Parent/child can identify actions and side effects of prescribed medications.
- 4) Child attains/maintains maximal level of skin integrity.
- 4 a) Parent/child can identify early signs and symptoms of skin breakdown, procedures to prevent skin breakdown and recommended treatment for skin lesions.
- b) Parent/child perform preventive measures such as daily skin checks, wearing non-restrictive clothing, safety with hot and cold, wheelchair cushions, paddings etc.

5) Child attains/maintains optimal pulmonary function.

- 5 a) Parent recognizes the signs and symptoms of pulmonary infection and other changes in pulmonary status, and identifies appropriate actions to take.
- b) Parent demonstrates knowledge of feeding and positioning techniques to prevent aspiration.
- c) Parent demonstrates knowledge of proper pulmonary hygiene techniques.
- d) Parent/child can identify actions and side effects of prescribed medications and can demonstrate correct administration.
- e) Parent demonstrates knowledge of use of ventilatory aids and appropriate actions to take if problems or malfunctions occur.
- f) Periodic assessment of pulmonary status.
- g) Child has minimal amount of excess secretions.
- h) Child is free from respiratory distress.

6) Child attains/maintains optimal musculoskeletal function.

- 6 a) Family demonstrates knowledge of proper body alignment and posture to prevent deformities.
- b) Family demonstrates knowledge of proper range of motion and stimulation activities to prevent contractures.
- c) Family demonstrates knowledge of appropriate use of adaptive equipment to prevent skeletal deformities.
- d) The child's body is maintained in proper body alignment to prevent deformities and contractures.

C. Functional

1) Child attains/maintains a maximal level of mobility consistent with level of neuromotor involvement.

- 1 a) Family can identify treatment plan necessary to achieve mobility.
- b) Child can demonstrate typical exercise routine.
- c) Family obtains prescribed adaptive equipment, assistive devices and mobility aids.
- d) Family can demonstrate knowledge of safe use of adaptive equipment, assistive devices and mobility aids.
- e) Family can demonstrate safe transfer techniques.
- f) Family demonstrates knowledge of treatment plan to facilitate gross and fine motor development.

2) Child attains and maintains maximal urine/bladder control.

- 2 a) Family demonstrates knowledge of urologic treatment plan.
- b) Child is free from urinary tract infections.
- c) Family obtains prescribed equipment/aids/supplies to assist in toileting.

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| 3) Child attains and maintains maximal stool control. | <ul style="list-style-type: none"> 3 a) Family demonstrates knowledge of bowel treatment plan. b) Family demonstrates knowledge of proper food and fluid intake to support healthy and regular bowel evacuation. c) Family obtains prescribed equipment/aids/supplies to assist in toileting. |
| 4) Child attains and maintains maximal oral motor skills. | <ul style="list-style-type: none"> 4 a) Documentation of swallowing studies/feeding evaluations, as necessary. b) Documentation of plan for progression of food textures, as necessary. c) Evaluation and follow-up, as prescribed by physician, by occupational therapist/physical therapist/speech therapist to maximize oral motor skills. d) Family demonstrates knowledge of treatment plan to promote development of oral motor skills. |
| 5) Child attains and maintains maximal communication skills. | <ul style="list-style-type: none"> 5 a) Child receives periodic speech-language evaluations. b) Family demonstrates knowledge of treatment plan to promote development of communication skills. |
| 6) Child attains/maintains age appropriate daily living skills within the framework of his/her disability. | <ul style="list-style-type: none"> 6 a) Family can identify the child's special safety needs related to the disability. b) Family can identify the child's self-help needs within developmental guidelines. c) Family teaches the child daily living, self-help skills (e.g. dressing, bathing, toileting, eating, etc.). d) Child can demonstrate skills compatible with highest developmental/educational level. e) Family can demonstrate use of adaptive equipment needed to facilitate attainment of daily living skills. |
| 7) Child attains/maintains maximal understanding of sexual and reproductive capabilities. | <ul style="list-style-type: none"> 7 a) Child can identify implications of his/her disability as it pertains to sexual function. |

D. Psychosocial

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| 1) Psychosocial response to handicapping condition is age appropriate. | <ul style="list-style-type: none"> 1 a) Achievement of age-appropriate socialization skills. b) Parent/child have information about support groups/peer groups. c) Child demonstrates positive expressions of self-esteem. d) Child participates in recreational activities, as appropriate to functional level. |
| 2) Educational/vocational goals achieved. | <ul style="list-style-type: none"> 2 a) Receives education in least restrictive environment with appropriate related services and supports. b) Achieves employment/post secondary educational placement/vocational training. |

E. Family satisfaction

1) Parent/child achieve satisfaction with outcomes of treatment.

- 1 a) Parent/child have input into care plan.
- b) Parent/child have access to choice of providers.
- c) Parent/child demonstrate knowledge of cerebral palsy condition, complications, treatment plan, available resources, parenting skills and support opportunities.
- d) Parent/child receive information about prevention and genetic counseling services available.

10/95

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