



Standards
of Care
& Outcome
Measures

***for Children With
Craniofacial
Deformities***

Developed By:
The Craniofacial Standards Committee
of Children With Medical Handicaps

Standards of Care for Children With Craniofacial Deformities

Definition	A craniofacial deformity is a congenital, developmental, or acquired deformity of the craniofacial skeleton and/or overlying soft tissue.
Goal	These standards are prepared to assure that children with significant craniofacial deformities achieve maximum habilitation or rehabilitation throughout developmental and educational years.
Care Needs	The complexity of craniofacial deformities requires a multidisciplinary approach to care, including medical, surgical, dental, psychosocial, communication, education, and vocational needs. Care needs must be managed by a plastic surgeon, pediatrician, or other pediatric medical specialist who is familiar with the treatment of children with these deformities. This physician assumes responsibility for coordinating the care of the team physicians, dentists, and allied health professionals who deliver the services required by these children.
Care Team	The care team should consist of a pediatrician, plastic surgeon, otolaryngologist, orthodontist, pediatric dentist, prosthodontist, oral surgeon, speech pathologist, audiologist, psychologist and/or social worker, and registered nurse. A coordinator should assume the administrative duties of the team. Consultation, as appropriate, should be available from a geneticist, radiologist, anesthesiologist, neurosurgeon, ophthalmologist, occupational therapist, physical therapist, and nutritionist. In addition, the child's primary care physician should provide information for the team, as well as receive communication from the team, regarding the child's care needs.
First Days of Evaluation	The care needs to be met by the craniofacial team are as follows: confirmation of diagnosis; assessment of family needs; genetic counseling as indicated; development of treatment plan; education of family regarding the specific anomaly, and the short and long term treatment plans; information on nutrition and feeding techniques provided to family; emotional/family support; referral to appropriate community resources; scheduling of regular evaluations; and beginning of ongoing communication with the primary care physician.
Content of Reevaluations	As the child with a craniofacial anomaly grows and develops, additional needs often become evident. These additional needs require involvement of other disciplines and implementation of new technologies and strategies. The elements for reevaluation of the child with a craniofacial anomaly are recommended by age group; diagnostic and therapeutic interventions are not specified. The listings are cumulative. It is recommended that a child entering the program for the first time would receive, as part of the initial evaluation, all items indicated through the child's age group. In addition to the specialized care required by the child with a craniofacial anomaly, provision for appropriate and usual well-child care should be made in accordance with the guidelines of the American Academy of Pediatrics' <i>Standards of Child Health Care</i> . Special emphasis should also be placed on routine ongoing dental care throughout the child's life. The reevaluation emphases/concerns are problem-oriented rather than treatment-oriented. It should also be stressed that types of conditions listed are not necessarily mutually exclusive. Due to the complexity of these conditions, more than one may be present in a child

with a craniofacial deformity. These lists have been designated to provide guidelines to promote quality care while maintaining the flexibility necessary for provision of individualized care for children with craniofacial anomalies.

CMH Services

Requests for diagnostic services for children with craniofacial deformities must be made by an appropriate CMH physician provider. For financially eligible children on the CMH treatment program, care must be managed and coordinated by a CMH approved craniofacial team.

Craniofacial Deformities Matrix

Age Group	Re-Evaluation Emphases and Concerns	Cleft Lip/ Palate	Maxillo-Mandibular Deformities	Cranio-Orbital Deformities	Soft Tissue Deformities
First years of life (0-2)	Genetic Counseling	X	X	X	X
	Surgical Repair(s)	X	0	X	X
	Identification of Middle Ear Disease	X	X	X	X
	Audiologic Evaluation	X	X	X	X
	Evaluation of Arch Segments	X	X	0	0
	General and Preventive Dental Care	X	X	X	X
	Family Support/Counseling/Education	X	X	X	X
	Neurosurgeon/Ophthalmologist Evaluation	0	0	X	0
Evaluation of Feeding/Nutrition	X	X	0	0	
Toddler and Pre-School Years (2-5)	Reconstruction Surgery as Indicated (including ears and other procedures)	X	X	X	X
	Treatment of Middle Ear Disease	X	X	X	X
	Evaluation and Treatment of Hearing, Speech and Language Skills/Problems	X	X	X	X
	Evaluation and Treatment of Skeletal/Dental/Functional Concerns	X	X	0	0
Primary and Middle School Years (6-12)	Evaluation and Treatment of Skeletal/Dental/Functional/Aesthetic Concerns	X	X	0	0
	Prosthetic Intervention as Indicated	X	X	X	X
	Educational Issues	X	X	X	X
	Psychological Evaluation	X	X	X	X
	Comprehensive Orthodontic Care	X	X	0	0
Adolescent and Young Adult (13-21)	Orthognathic Surgery as Indicated	X	X	X	0
	Vocational Counseling	X	X	X	X
	Genetic Counseling	X	X	X	X
X—Yes 0—No	Personal Appearance/Cosmesis	X	X	X	X

Craniofacial Outcome Criteria

Outcomes

Process Measures

A. Quality Management

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| 1) Child's care for the craniofacial condition is managed by an established multidisciplinary craniofacial team. | 1 a) Referral made to the multidisciplinary team for initial evaluation within the first few weeks of life, or upon identification of suspected craniofacial anomaly.
b) Treatment plan developed and implemented on the basis of team recommendations.
c) Family has access to appropriate providers with each visit to the team.
d) Care coordination is provided by the team, with provision for local care whenever possible.
e) Complex diagnostic and surgical procedures restricted to major centers.
f) Documentation of long and short term outcomes of the treatment plan.
g) Family has access by phone to team members at times other than regularly scheduled appointments.
h) Team actively solicits family/child's participation and collaboration in treatment plan. |
| 2) Service coordination is provided at both the team and local levels. | 2 a) The child has an identified team and local (PHN) service coordinator.
b) Documentation of a comprehensive plan developed by the family, team and local service coordinators which addresses the medical, dental, social, vocational, educational, nutritional, and recreational needs of the child.
c) The comprehensive service plan is updated at least annually.
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 who is an active or extended member of the team.
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 or other problems; provision of appropriate anticipatory guidance.
e) Mutual communication between the specialty team, the primary care physician and public health nurse 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. |

B. Physiological

- 1) Surgical correction or intervention of soft tissue or bony deformity at appropriate time.
 - 1 a) Initial surgical repairs of lip/palate are done by the team surgeon within the first two years of life.
 - b) Additional reconstructive surgery is initiated, as needed.
 - c) Family demonstrates understanding about surgical procedure and long term plans for reconstruction.

- 2) Maintains adequate nutritional status.
 - 2 a) Documentation of periodic nutrition assessment, including pre and post surgeries.
 - b) Documentation of weight for height (length) ratio on National Center for Health Statistics (NCHS) growth grids.
 - c) Family demonstrates knowledge of appropriate feeding techniques and intervention for regurgitation and aspiration.
 - d) Family can identify signs of adequate growth and interventions for growth failure.

- 3) Dentition maintained in optimal condition.
 - 3 a) Regular dental appointments with appropriate dental providers.
 - b) Documentation of current dental management plan.
 - c) Treatment of dental and periodontal disease.
 - d) Evaluation/treatment of malocclusions at appropriate intervals.
 - e) Family demonstrates knowledge of proper oral hygiene techniques.
 - f) Regular monitoring of dental and facial growth and development.

- 4) Absence of middle ear disease.
 - 4 a) Regular monitoring of the ears, nose and throat by an otolaryngologist.
 - b) Medical/surgical treatment of middle ear disease by an otolaryngologist.
 - c) Evaluation/treatment of related conditions by an otolaryngologist.
 - d) Family demonstrates knowledge of signs and symptoms of otitis media and appropriate actions when present.

C. Functional

- 1) Speech, language and communication potential are maximized.
 - 1 a) At approximately the child's first birthday, parents are counseled regarding risk factors for communication disorders, as well as methods of speech and language stimulation, in children who have a history of cleft lip/palate.
 - b) Language skills are screened at approximately age 2.
 - c) Between the ages of 3 to 3 1/2, or after child is communicating with phrases and short sentences, a complete speech-language evaluation is done. If problems are identified, treatment is initiated immediately and continued until the child's communication skills are age-appropriate.
 - d) Once communication skills are deemed age-appropriate or normal, evaluations are done whenever communication problems are noted by the parents or by teachers.
 - e) Family demonstrates knowledge of, and participates in, the child's program to improve speech, language and communication.
 - f) Family demonstrates knowledge of early intervention and educational services.

- 2) Maintenance/achievement of optimal hearing.
 - 2 a) Appropriate assessment of hearing sensitivity for each ear before the age of 9 months.
 - b) Follow-up audiological examinations annually and based on history of ear disease or hearing loss.
 - c) Evaluation for amplification in the case of persistent hearing loss.
 - d) Referral to the school district or county early intervention collaborative group for appropriate educational services if hearing loss is documented.
 - e) Regular monitoring of hearing thresholds and functions of amplification system.

D. Psychosocial

- 1) Psychosocial response to handicapping condition is age-appropriate.
 - 1 a) Achievement of age-appropriate socialization skills.
 - b) Family/child have information about support groups/peer groups.
 - c) Child demonstrates positive expressions of self-esteem.
 - d) Child participates in recreational activities.

- 2) Educational/vocational goals achieved
 - 2 a) Receives education in least restrictive environment with appropriate related services and supports.
 - b) Achieves age appropriate grade levels.
 - c) Achieves employment/post secondary educational placement.

E. Family Satisfaction

- 1) Child/family achieve satisfaction with outcomes of treatment.
- 1 a) Family/child have input into care plan.
- b) Family/child have access to choice of providers.
- c) Family/child demonstrate knowledge of craniofacial condition, complications, treatment plan, available resources, parenting skills and support opportunities.
- d) Family/child receive information about prevention and genetic counseling services available.
- e) Family/child receive information about cosmetic options to enhance appearance.

10/95

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