

Introduction

Cleft and craniofacial teams are comprised of experienced and qualified professionals from medical, surgical, dental and allied health disciplines working in an interdisciplinary and coordinated system. The purpose and goal of teams are to ensure that care is provided in a coordinated and consistent manner with the proper sequencing of evaluations and treatments within the framework of the patient's overall developmental, medical and psychological needs.

As a means to verify the quality of the care provided by such teams, the American Cleft Palate-Craniofacial Association (ACPA) has developed an approval process in order to provide:

- Standards that identify essential characteristics of quality for team composition and functioning in order to facilitate the improvement of team care
- Accurate information to patients and families/caregivers regarding services provided by those teams that meet specified standards

These standards have received widespread peer-review and represent expectations for approval of teams providing care to individuals with clefts and craniofacial conditions.

It is important to note that ACPA Team Approval is a voluntary and non-exclusionary process. There is no judgment or statement of quality made about established teams that have not selected to apply for approval; nor is holding approval required for health care professionals to organize and advertise themselves as a team. However, all teams that do choose to undergo an external evaluation and demonstrate compliance with the standards for team care will be listed as ACPA Approved Teams. ACPA Approved Teams are the teams ACPA encourages patients and families to consider first for cleft and craniofacial healthcare needs.

The ACPA has established standards for care and identified the following six components as essential to the quality of care provided by interdisciplinary teams of health care specialists to patients with cleft lip/palate or craniofacial anomalies, regardless of the specific type of disorder:

- Team Composition
- Team Management and Responsibilities
- Patient and Family/Caregiver Communication
- Cultural Competence
- Psychological and Social Services
- Outcomes Assessment

Standards for Interdisciplinary Team Care

ACPA has adopted the following standards as necessary conditions for approval of both cleft palate and craniofacial teams. Standards appear in **bold**; *italicized* information provides guidance on interpretation or further clarification of the standards.

Standard 1: Team Composition

- 1a. The team includes a designated patient care coordinator to facilitate the function and efficiency of the team, ensure the provision of coordinated care for patients and families/caregivers and assist them in understanding, coordinating and implementing treatment plans.**

The team has a clearly identified patient care coordinator who has responsibility for facilitating the operation of the team. The roles and responsibilities of the coordinator are clearly identified. The coordinator ensures that each patient receives care that is comprehensive and involves interdisciplinary planning to achieve maximum habilitation with efficient use of parent/caregiver and patient time and resources. The coordinator is identified on all materials containing team listings.

- 1b. The team includes speech-language pathology, surgery and orthodontic specialties.**

The team must have, as a minimum core, professionals from the speech-language pathology, surgery, and orthodontics specialties who participate in team meetings as appropriate to specific patient needs. The participation of these individuals should be documented in each patient's team reports.

- 1c. The team demonstrates access to professionals in the disciplines of psychology, social work, audiology, genetics, general and pediatric dentistry, otolaryngology and pediatrics/primary care.**

The team must maintain a list of reliable community resources for any services that are not provided by the team itself. Some record of assessment and/or treatment follow-up should exist in the centralized team record.

Craniofacial (surgery involving a transcranial procedure) teams and cross-specialty teams (both cleft palate and craniofacial) must meet standards 1a through 1c related to team composition, as well as the following standard.

- 1d. The craniofacial team must include a surgeon trained in transcranial cranio-maxillofacial surgery and access to a psychologist who does neurodevelopmental and cognitive assessment. The results of the neurodevelopmental and cognitive assessment must be part of the CFT team assessment record. The team also must demonstrate access to refer to a neurosurgeon, an ophthalmologist, a radiologist, and a geneticist. The participation of these individuals should be documented in each patient's team report.**

The qualifications of all team members should be evident in terms of appropriateness of training and practical and educational experiences specific to the responsibilities and procedures to be performed. Team members must hold credentials of the appropriate professional organizations as well as state and/or provincial licensing.

Standard 2: Team Management and Responsibilities

- 2a. The team has a mechanism for regular meetings among core team members to provide coordination and collaboration on patient care.**

The principal role of the interdisciplinary team is to provide integrated case management to assure quality and continuity of patient care and longitudinal follow-up. Each patient seen by the team requires comprehensive, interdisciplinary treatment planning to achieve maximum habilitation with efficient use of parent/caregiver and patient time and resources. Regular meetings help to ensure coordination of care and collaboration among team members. While face-to-face meetings are preferred, it is recognized that teams may use alternative means to interact. Teams should demonstrate their mechanism for achieving consensus on treatment plans.

- 2b. The team has a mechanism for referral to and communication with other professionals.**

The team has a process for referring patients to local care providers when necessary and appropriate.

The team has and implements a process for information exchange with schools, primary care professionals, outside agencies, and other professionals involved with the welfare of the patient.

The team must have a process for obtaining informed consent consistent with federal, state, and institutional requirements.

- 2c. The team re-evaluates patients based on team recommendations.**

Subsequent evaluations should be scheduled at regular intervals, the frequency and specific content of each of those evaluations being determined by the condition and needs of the individual patient and family/caregiver.

- 2d. The team must have central and shared records.**

Comprehensive records on each patient must include histories, diagnoses, reports of evaluations, treatment plans, and reports of treatment. Supporting documentation may include photographs, radiographs, dental models, and audio taped speech records.

Standard 3: Patient and Family/Caregiver Communication

- 3a. The team provides appropriate information to the patient and family/caregiver about evaluation and treatment procedures orally and in writing.**

Teams should assist parents/caregivers in making informed decisions on the child's behalf and preparing the child and themselves for all recommended procedures. Parents/caregivers must be given information about recommended treatment plans and any alternatives, benefits, and risk factors. Communication with the patient should follow after each team evaluation.

- 3b. The team encourages patient and family/caregiver participation in the treatment process.**

Teams must have mechanisms that ensure the family/caregiver and patient have opportunities to play an active role in treatment decisions. The team should educate parents/caregivers about the importance of informing their children about their condition and encourage them to become active participants in treatment decisions (i.e., when the child is mature enough to do so, he or she should be present and have opportunity to have input in treatment decisions.)

- 3c. The team will assist families/caregivers in locating resources for financial assistance necessary to meet the needs of each patient.**

Patients and families/caregivers must be made aware of resources such as federal, state and provincial regulations specifically governing the treatment of cleft/craniofacial anomalies (e.g., insurance, state agencies, Public Law 94-142, 504s, and individual educational plans).

Standard 4: Cultural Competence

- 4a. The team demonstrates sensitivity to individual differences that affect the dynamic relationship between the team and the patient and family/caregiver.**

Teams demonstrate sensitivity and flexibility in provision of care to accommodate linguistic, cultural, and ethnic diversity among patients and their families/caregivers and ensure that appropriate interpreters are available to assist in both verbal and written communication.

- 4b. The team treats patients and families/caregivers in a non-discriminatory manner.**

Services are provided without regard to race, color, religion, sex, national origin, disability, age, sexual orientation, or status as a parent/caregiver. Teams must be in compliance with all applicable federal, state, provincial, and local laws prohibiting discrimination (e.g., the current versions of the Americans with Disabilities Act, the Civil Rights Act, the Age Discrimination in Employment Act, the Age Discrimination Act, Title IX of the Education Amendments to the Higher Education Act, the Rehabilitation Act, etc.)

Standard 5: Psychological and Social Services

- 5a. The team has a mechanism to initially and periodically assess and treat, as appropriate, the psychological and social needs of patients and families/caregivers and to refer for further treatment as necessary.**

The team must have available, either as part of the team or for referral, social workers and psychologists who are capable of addressing the psychological and social needs of the patient and family/caregiver.

- 5b. The team has a mechanism to assess cognitive development.**

Teams must ensure that assessments for cognitive development and learning disabilities have been conducted at appropriate time intervals so that each patient receives appropriate educational services from infancy throughout adolescence. Documentation of these assessments and recommendations should be part of the patient's team record.

Craniofacial (surgery involving a transcranial procedure) teams and cross-specialty teams (both cleft palate and craniofacial) must meet Standards 5.1 and 5.2 related to psychological and social services, as well as the following standard.

- 5c. The craniofacial team conducts formal assessment of cognitive functioning of patients when deemed necessary.**

Cognitive psychometric testing must be performed, when necessary, on patients whose age is 4 or older and who have a craniofacial condition requiring transcranial surgery.

Standard 6: Outcomes Assessment

- 6a. The team uses a process to evaluate its own performance with regard to patient assessment, treatment, or satisfaction and to make improvements as a result of those evaluations.**

The team documents its treatment outcomes, including baseline performance and changes over time. Teams must conduct periodic retrospective or prospective studies to evaluate treatment outcomes. The team must also have a quality management system to evaluate patient/family satisfaction.