



ACPA

American Cleft Palate
Craniofacial Association

Standards for Approval of Cleft Palate and Craniofacial Teams

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 a team is to ensure that timely, evidence-based 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 psychosocial needs.

The American Cleft Palate Craniofacial Association (ACPA) has developed an approval process for teams in order to provide:

- Standards that identify essential characteristics of quality for team composition and functioning in the context of collaborating healthcare systems 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 are based on the ACPA *Parameters of Care*, which have received widespread peer-review, and represent expectations for approval of teams providing care to individuals with clefts and craniofacial differences.

ACPA Team Approval is a voluntary and non-exclusionary process. There is no judgment or statement of quality made about teams that have selected not to apply for approval; nor is holding approval required for health care professionals to organize and advertise themselves as a team.

All teams that choose to undergo an external evaluation and report 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 seven components as essential to the quality of care provided by interdisciplinary teams of health care specialists to patients with cleft lip/palate or craniofacial differences, regardless of the specific diagnosis:

1. Team Composition
2. Team Management and Responsibilities
3. Patient and Family/Caregiver Communication
4. Transition and Adult Care
5. Social Drivers of Health
6. Psychological and Social Services
7. 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** followed by 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 and implementing treatment plans.**

The team has at least one patient care coordinator who is clearly identified on all materials containing team listings. The coordinator(s)' responsibilities are to:

- Facilitate efficient team functioning by organizing interdisciplinary care across all clinical areas and specialties.
- Ensure that each patient receives care that is comprehensive and involves interdisciplinary planning to achieve optimal outcomes with efficient use of patient and parent/caregiver time and resources.
- Provide oversight of the team during clinical visits, ensure the organization and navigation of the providers, and identify and resolve any challenges that may arise.
- Be accountable for communication between team members and communication provided to the patients and families/caregivers during and after the visit (e.g., the team report) as well as ensuring any necessary follow-up is conveyed.

- 1b. The team includes a team leader who is responsible for ensuring that the team provides comprehensive, effective, and ethical interdisciplinary care.**

The team has at least one clearly identified leader who is a cleft and/or craniofacial provider. The team leader(s)' responsibilities are to:

- Oversee the operation of the team.
- Ensure the team is in compliance with the ACPA Standards of Approval and follows the *Parameters of Care*.
- Make sure that all team members are aware of and in adherence to ACPA's Code of Ethics.

- 1c. The core team includes speech-language pathology, orthodontic, and surgical specialties.**

The core team must have at minimum:

- A speech-language pathologist
- An orthodontist
- A surgeon trained in cleft lip/palate (CL/P) surgeries. Surgeons who perform CL/P surgery may include, but are not limited to, plastic and maxillofacial surgeons, otolaryngologists, and oral and maxillofacial surgeons.

These core team members must meet the following requirements:

- Participate in team evaluations (in which patients receive face-to-face evaluations by the disciplines represented on the team) and team meetings (in which patient findings are discussed by team members and team recommendations are made) as appropriate to individualized patient needs and their participation, including assessments and recommendations, should be documented in each patient's team reports.

- Have completed appropriate training and practical and educational experiences specific to the responsibilities and procedures to be performed. Have experience with and exposure to a sufficient number of patients with cleft lip/palate and/or other craniofacial differences to maintain their clinical skills at the highest level.
- Hold credentials of appropriate professional organizations as well as state and/or provincial licensing.
- Have an understanding of ACPA's *Parameters of Care* with a commitment to practice within those recommendations.

The team should assist members in keeping current with their specialties by supporting and encouraging participation in cleft and craniofacial-specific continuing education activities and attendance at professional meetings.

1d. The team either includes or refers to professionals in the disciplines of nursing, anesthesia, psychology, social work, audiology, genetics, general and pediatric dentistry, prosthodontics, oral and maxillofacial surgery, otolaryngology, plastic and maxillofacial surgery, and pediatrics/primary care. The team must designate providers/entities who address feeding, growth, and nutrition; airway and breathing; and sleep health and hygiene.

Although not required, it is encouraged that these professionals participate as regular team members by attending team evaluations and team meetings. The team must:

- Maintain a list of reliable institutional and community referrals for any services that are not provided by the team itself.
- Assessment, treatment, and/or follow-up from these referrals should be included in the centralized team record.
- Share the *Standards and Parameters of Care* with providers referred to outside of the team.

Craniofacial teams and cross-specialty teams (both cleft palate and craniofacial) must also meet the following standard.

1e. The craniofacial team must also include a surgeon trained in intracranial craniomaxillofacial surgery. The team must include or refer to a neurosurgeon, ophthalmologist, and radiologist.

The qualifications of the required craniofacial team members should be evident in terms of appropriate 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.

The team must:

- Maintain a list of reliable institutional and community referrals for any services that are not provided by the team itself for craniofacial care.
- Assessment, treatment, and/or follow-up from these referrals should be included in the centralized team record.
- Share the *Standards for Approval and Parameters of Care* with providers referred to outside of the team.

Standard 2: Team Management and Responsibilities

2a. The team has regular interdisciplinary meetings including core and other team members to provide coordination and collaboration on patient care.

The principle role of the interdisciplinary team is to provide integrated care management to ensure quality and continuity of patient care and longitudinal follow-up. Each patient seen by the team requires comprehensive, interdisciplinary treatment planning to achieve maximum coordination of personalized treatment with efficient use of parent/caregiver and patient time and resources. To achieve this:

- Regular meetings are needed 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. Virtual meetings can allow team members to participate from any location in real time.
- The team should demonstrate a mechanism for achieving consensus on treatment plans.
- The results of the team meeting must be documented in a written team report. A report should be a single document rather than a compilation of individual progress notes and include:
 - Participation from the core team members at minimum.
 - The names and disciplines of additional providers who examined the patient.
 - The evaluation date, diagnoses, treatment history, findings, and recommendations of each provider who examined the patient.
 - An overall team consensus recommendation.
 - The individual who generated the team report.

2b. The team has a mechanism for referral to and communication with professionals outside the team.

The team has a process for two-way communication with outside entities including:

- Referring patients to primary and specialty care providers outside of the team when appropriate with confirmation of scheduling and exchange of records.
- Information exchange with schools, universities, outside agencies, and other professionals involved with the welfare of the patient. These communications must abide by HIPAA regulations in the United States or PIPEDA in Canada.

2c. The team evaluates patients at regular intervals.

The team has a process for scheduling evaluations at specified developmental milestones that guide treatment. The frequency, providers seen, and specific content of each evaluation is determined by the needs of the individual patient.

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

The team has a system for storing and sharing records among all team members, preferably in electronic format. Comprehensive records on each patient must include:

- Histories, diagnoses, reports of evaluations, reports of treatment, and treatment plans.
- Evaluations and treatments performed by outside referrals.
- Supporting documentation may include photographs, radiographs, dental models, and audio taped speech records.

Standard 3: Patient and Family/Caregiver Communication

3a. The team provides oral and written information to the patient and the family/caregiver that is clear, accurate and complete regarding evaluation and treatment procedures.

The team should provide patients and family/caregivers with all relevant information regarding the evaluation and treatment to maximize understanding of the patient's findings, diagnoses, recommendations, and procedures.

- This information should be provided both verbally and in writing in their preferred language.
- The findings and recommendations of each team member should be provided to patients and family/caregivers following each team evaluation as a single report. It is recommended that the team report includes a summary written at an accessible reading level.

3b. The team ensures participation of the patient and family/caregiver in the treatment process.

The team must have mechanisms that ensure the patient and family/caregiver are given 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 early in development and encourage them to become active participants in treatment decisions.
- Formally recognize that patients, as developmentally appropriate, and families/caregivers are essential partners in decision-making. Shared decision making requires providers to actively work to understand the patient's values and priorities to guide choices. If the patient is not yet active in decision-making, the parents/guardians are active participants.
- Treatment discussions should include all risks, benefits, alternatives, and the expected consequences of non-treatment.

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

Patients and families/caregivers should receive information from the team about:

- Applicable federal, state, and provincial regulations (e.g., public and private insurance, state agencies, 504s, and Individual Education Programs) and community resources.
- Available financial resources (including for those who do not have insurance eligibility).

Standard 4: Transition and Adult Care

4a. The team provides transition planning to facilitate coordinated care into adulthood and/or if patients relocate.

A designated team member(s) should coordinate transition of care with a focus on provision of individualized patient-centered care and treatment planning. The team should:

- Provide patients and families/caregivers with documentation containing a comprehensive medical history summary, treatment received, and recommendations for future care across specialties. Reports should serve the dual purpose of informing care for healthcare providers and include language accessible to patients to guide their own care.

4b. The team builds health care management skills starting in early adolescence.

A designated team member(s) should:

- Support, as appropriate to individual patients, learning management of their own care (e.g., participating in treatment decisions, understanding consent, knowledge of their medical history, making medical appointments, and familiarity with insurance resources).
- Give guidance to patients transitioning to adult care on self-advocacy for continuing their care and seeking the necessary resources for financial assistance.
- Assist families of patients with cognitive delays or similar needs that impact their ability to independently manage care as adults in accessing appropriate legal and community resources.

4c. The team refers to adult healthcare providers for addressing ongoing care needs and remains available to patients for additional referrals across the lifespan.

The team must:

- Make referrals available at any age of presentation for concerns related to cleft and/or craniofacial differences, with resources available to support financial assistance.
- Facilitate transfer of treatment records to adult healthcare providers.
- Be available to consult with adult healthcare providers to assist with appropriate continuity of care.

As possible, the team is encouraged to provide ongoing coordinated cleft/craniofacial care across the lifespan based on individual patient needs.

Standard 5: Social Drivers of Health

5a. The team demonstrates sensitivity to individual differences that affect the relationship between the team and the patient and family/caregiver.

The team demonstrates sensitivity to linguistic, cultural, ethnic, gender, sexual orientation, disability, socioeconomic, and religious needs of patients and family/caregivers. The team must:

- Provide appropriate accommodation for patients and family/caregivers to facilitate these needs, including translation/interpretation services for written and verbal communications.
- Complete regular training in appropriate care addressing social determinants of health.

5b. The team treats patients and families/caregivers in a non-discriminatory manner.

The team must ensure:

- Services are provided without regard to race, color, religion, sex, gender, national origin, disability, age, sexual orientation, or legal status as a patient and parent/caregiver.
- Care is provided in compliance with all applicable federal, state, provincial, and local laws prohibiting discrimination.

Standard 6: Psychological and Social Services

6a. The team has a mechanism for ongoing screening for psychological and social needs of patients and families/caregivers and to provide or refer for further treatment as necessary.

The team must:

- Have one or more designated provider(s) who universally screen all patients and families throughout development for psychosocial concerns and social engagement through interview and/or screening questionnaires.
- Have available, either as part of the team or by referral, qualified behavior or mental health professionals (e.g., social workers, and psychologists, pediatricians, developmental-behavioral pediatricians, psychiatrists, professional counselors, marriage and family therapists, or psychiatric advanced practice providers) who are capable of addressing the psychological and social needs of the patient and family/caregiver.

6b. The team has a mechanism to monitor age-appropriate cognitive development, learning abilities, and receipt of educational services and to provide or refer for assessment and educational advocacy as necessary.

The team must:

- Have one or more designated provider(s) who monitor age-appropriate cognitive development, learning abilities, and educational services throughout development.
- Have available, either as part of the team or by referral, a qualified provider who conducts neurodevelopmental and cognitive assessments.
- Conduct or refer for assessments for cognitive development and learning disabilities at appropriate time intervals, as necessary, which may include assessments completed through early intervention programs and Individualized Education Programs (IEPs).
- Assist with or refer for educational advocacy so that each patient receives appropriate educational services from infancy throughout adolescence.
- Document these assessments and recommendations as part of the patient's team record.

Standard 7: Outcomes Assessment

7a. The team measures and reviews outcomes at regular intervals.

The team must:

- Develop and maintain a structured process to evaluate its own performance to ensure that care aligns with established timelines, evidence-based practices, and benchmarks.
- Review, document, and monitor evaluation activities at defined intervals, including regular reviews of clinical outcomes drawn from the *Parameters of Care*.

7b. The team has a process to improve patient and family satisfaction based on feedback.

The team must:

- Assess patient and family satisfaction through surveys and direct feedback mechanisms.
- Analyze input to identify opportunities for improving coordination of care, communication, and overall patient experience.
- Ensure all assessments and resulting improvements are documented and monitored.

7c. The team has a mechanism for implementing quality improvement.

The team must:

- Discuss findings from clinical outcomes, patient safety, adverse events, and satisfaction reviews during scheduled team meetings dedicated to quality improvement.
- Identify improvement priorities, implement targeted actions, and subsequently evaluate their effectiveness.

- Ensure all meetings are documented and made available to the team.