ACPA
American Cleft Palate
Craniofacial Association

Parameters of Care

For Evaluation and Treatment of Individuals with Cleft Lip/Palate and/or Other Craniofacial Conditions

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1: Statement of Purpose

The American Cleft Palate Craniofacial Association's (ACPA) Parameters of Care (ACPA Parameters) for Evaluation and Treatment of Individuals with Cleft Lip/Palate (CL/P) and/or Other Craniofacial Differences aims to provide an up-to-date summary to help guide the care of individuals with cleft-craniofacial conditions. The document is a critical driver of ACPA's mission to facilitate access to high quality care for individuals with CL/P and craniofacial conditions and to promote team care as the best model for cleft-craniofacial care. Although this document is intended primarily for healthcare professionals, patients, families, and other stakeholders may find the content useful for informed decision-making. ACPA will develop related resources that are tailored specifically for patients and families.

Figure 1 shows where the ACPA Parameters fit in with other ACPA resources and programs, and how they promote access to evidence-based information that informs care planning and delivery.[1]

ACPA's Parameters are driven by evidence-based research, including numerous studies published in the *Cleft Palate Craniofacial Journal* (CPCJ).[2] They have been shaped by clinical

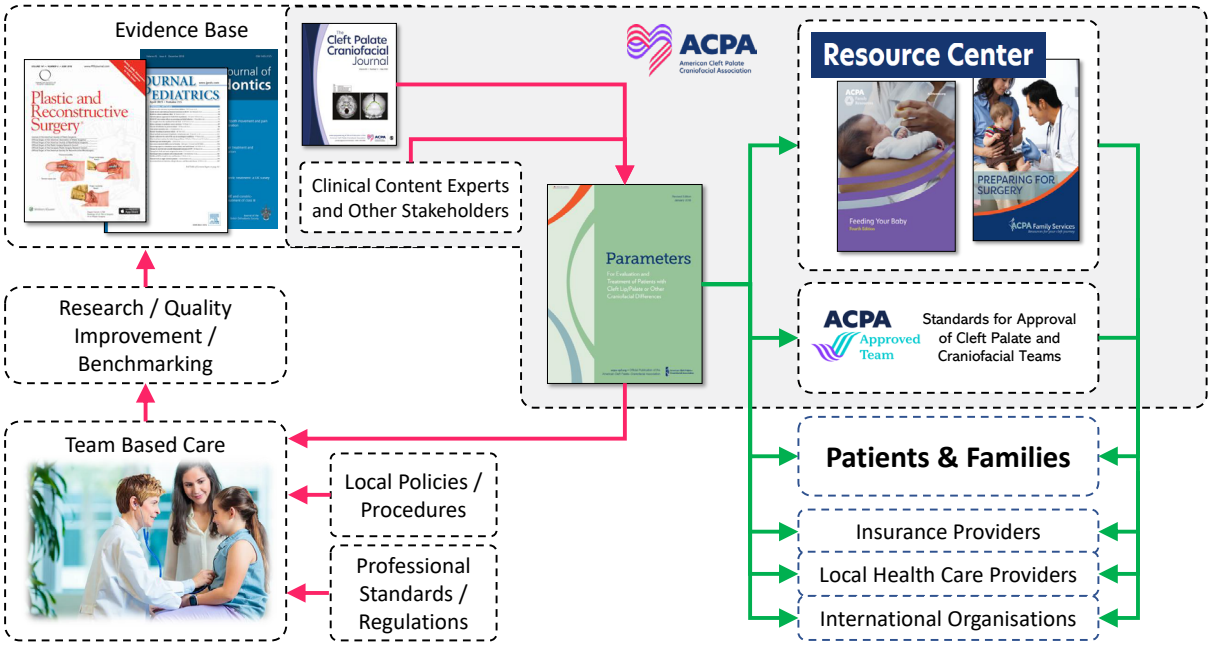

FIGURE 1: Role of the Parameters of Care for Evaluation and Treatment of Patients with Cleft Lip/Palate and/or Other Craniofacial Differences in relation to other ACPA resources.

content experts from the cleft and craniofacial fields. The ACPA Parameters provide a framework for care delivery which, in conjunction with local standards, regulations, policies, and procedures, helps inform high quality care. When this care is monitored, measured, and modified through an active quality management program (see Interdisciplinary Teams), new lines of research are identified and the evidence base for diverse aspects of care for patients with CL/P and/or other craniofacial differences is enhanced. This new knowledge will be incorporated into future iterations of the ACPA Parameters, ensuring that stakeholders can always access the best information to guide care planning and delivery. Ultimately, this information empowers stakeholders and promotes shared decision-making.

2: Introduction

About Cleft and Craniofacial Differences

Cleft lip, cleft palate, craniosynostosis, and conditions that affect development of the 1st and 2nd branchial arches are the most common congenital craniofacial differences.[3–6] These conditions can occur in isolation or in combination with other diagnoses or syndromes. The healthcare needs of children with CL/P and/or other craniofacial differences are best managed by an interdisciplinary cleft and/or craniofacial team (see Interdisciplinary Teams). The importance of these teams is reflected in the frequency with which they are referenced throughout the ACPA Parameters. Some interdisciplinary teams focus primarily on the care of patients with CL/P, while other teams focus the care for patients with other craniofacial differences. Some interdisciplinary teams provide care for children with CL/P and other craniofacial differences.

Principles of Cleft and Craniofacial Care

ACPA codified ten principles of interdisciplinary cleft and craniofacial care at the 1991 ACPA consensus meetings (Table 1).[7] These principles apply to care delivery for patients with CL/P and/or other craniofacial differences regardless of the patient's geographic location.

Relationship Between Principles and Parameters of Cleft and Craniofacial Care

The principles in Table 1 provide a broad framework under which more detailed 'parameters of care' are implemented. These are recommendations for the type and timing of specific elements of cleft and/or craniofacial care that care teams, patients, and families determine are appropriate as well care coordination strategies that are needed to deliver that care.

Rather than focusing on clinical disciplines (e.g. audiology, speech-language pathology, dentistry), the updated ACPA Parameters present recommendations in a problem-based context that targets optimal health and well-being. They offer detail on specific healthcare needs related to, for example, hearing, speech, and dental health. The ACPA Parameters are divided into four sections:

Interdisciplinary Teams reviews key elements of team care for patients with CL/P and other craniofacial differences. Establishing Care with the Cleft / Craniofacial Team outlines the clinical needs of neonates, including airway management, sleep, feeding, growth and nutrition and other topics. Longitudinal Evaluation and Care provides information on various components of cleft and craniofacial care after the initial contact and an initial treatment plan is established. The ACPA Parameters conclude with a description of Transition to Adult Care.

TABLE 1: Principles of Interdisciplinary Cleft and Craniofacial Care

I	Management of patients with craniofacial differences is best provided by an inter-disciplinary team of specialists.
II	Optimal care for patients with craniofacial differences is provided by teams that see sufficient numbers of patients each year to maintain clinical expertise in diagnosis and treatment.
III	The optimal time for the first evaluation is within the first few weeks of life and, whenever possible, within the first few days. However, referral for team evaluation and management is appropriate for patients at any age.
IV	From the time of the first contact with the child and family, every effort must be made to assist the family in adjusting to the birth of a child with a craniofacial difference and to the consequent demands and stress placed upon the family.
V	Caregiver(s) must be given information about recommended treatment procedures, options, risk factors, benefits, and costs to assist them in: a) Making informed decisions on the child's behalf b) Preparing the child and themselves for all recommended procedures. The team should actively solicit family participation and collaboration in treatment planning. c) Participating in care decisions when the child is mature enough to do so.
VI	Treatment plans should be developed and implemented on the basis of team recommendations.
VII	Care should be coordinated by the team but should be provided at the local level whenever possible; however, complex diagnostic and surgical procedures should be restricted to centers with the appropriate facilities and experienced care providers.
VIII	It is the responsibility of each team to be sensitive to linguistic, cultural, ethnic, psychosocial, economic, and physical factors that affect the dynamic relationship between the team and the patient and family.
IX	It is the responsibility of each team to monitor both short-term and long-term outcomes. Thus, longitudinal follow-up of patients, including appropriate documentation and record-keeping, is essential.
X	Evaluation of treatment outcomes must take into account the satisfaction and psychosocial well-being of the patient as well as effects on growth, function, and appearance.

3: Interdisciplinary Teams and Care Coordination

Last revised in November 2022, ACPA's Standards for Approval of Cleft Palate and Craniofacial Teams[8] (Standards for Teams) describes six topics that underpin the ability of interdisciplinary teams to deliver high quality care to patients with CL/P and/or other craniofacial differences:

- Team composition
- Team management and responsibilities
- Patient and family/caregiver communication
- Cultural competence
- Psychological and social services
- Outcomes assessment

As noted in the Standards for Teams, "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." In this framework, patients and families should be fully informed of treatment options and associated risks and benefits; they should be encouraged to ask questions about their care and teams should engage actively in these conversations. These discussions should promote an ongoing process of shared decision-making.

Figure 2 shows how interdisciplinary teams support patients and their families, and how research, local providers, and other factors inform and enhance team-based care.

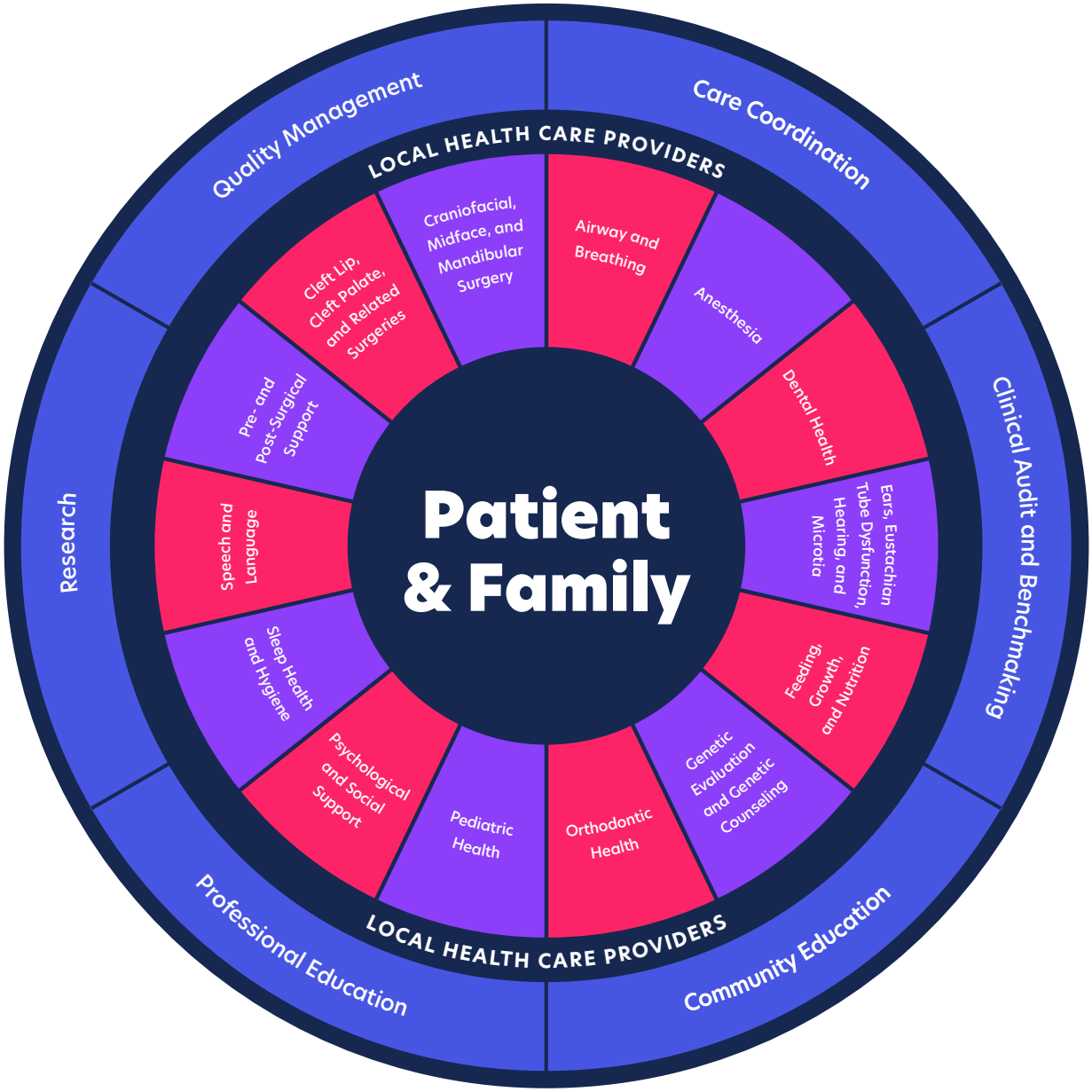

FIGURE 2: Interdisciplinary team care and the role of research, care coordination, and other factors in supporting patients with CL/P and craniofacial differences.

The newly updated ACPA Parameters complement the Standards for Teams by focusing on specific aspects of care that may be recommended for patients and families. However, several aspects from the Standards for Teams warrant emphasis because they underpin three themes that appear throughout this document:

- Care Coordination
- Patient/family education and engagement
- Quality improvement

The Standards for Teams also offer guidance on a fourth theme that drives high-quality patient care: team members' longitudinal experience with, and access to sufficient numbers of patients with CL/P and/or other craniofacial differences to ensure their ability to maintain clinical skills at the highest level. Given the emphasis on these themes, it is useful to reiterate selected Standards for Teams and supplemental guidance in the context of ACPA's Parameters.

Care Coordination

Caring for patients with CL/P and/or other craniofacial differences requires ongoing management of interdependencies across many clinical areas and specialties. This feature of team-based care underscores the importance of coordination, communication, and information exchange among team members. The standards below reflect the importance of ensuring that all aspects of care are fully addressed and coordinated in collaboration with the patient's family.

ACPA's Standards for Teams includes four coordination-related elements that are linked to multiple aspects of care delivery:

Standard 1a

The team includes a designated patient care coordinator.

Standard 2a

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

Standard 2b

The team has a mechanism for referral to and communication with other professionals.

Standard 2d

The team must have central and shared records.

The elements listed below provide a foundation for high-quality care, and they appear throughout this document.

- Designate staff with coordination responsibilities to facilitate efficient team functioning and care coordination for patients and families.
- Maintain centralized and comprehensive patient records that include diagnoses, histories, previous evaluations and treatment results, recommended treatment plans, and supporting documentation such as photographs, radiographs, dental models, and speech recordings.
- Convene regularly scheduled face-to-face or video meetings to discuss findings, treatment options and planning, and recommendations for each patient.
- Evaluate patients at regular intervals, with the frequency and content determined by the patient's condition and the needs and preferences of the patient and family.
- Develop a longitudinal treatment plan for each patient that is updated as needed by craniofacial growth and development, treatment outcomes, patient preferences, and therapeutic advances.
- Communicate on an ongoing basis with community-based providers and invite these providers to participate in team meetings involving their patients.
- Provide families with information for educational planning (e.g., individual education plans).
- Assist families to plan for treatment in a new geographic location by referring them to a new interdisciplinary team and facilitating contact with that team. (see Standards for Teams).
- Assist adolescents and their families to plan for the transition to adult care providers where appropriate and feasible.

Patient and Family Education and Engagement

Establishing a collaborative relationship with patients and their families greatly facilitates many aspects of patient-centered care such as the team's ability to share information, discuss treatment options, prepare patients for optimal outcomes, and coordinate care with community-based providers. Ongoing patient and family engagement and coordination with team members are critical for successful outcomes. This work is often facilitated by a nurse, genetic counselor, social worker, or another designated team member.

ACPA's Standards for Teams includes three education and engagement-related items:

Standard 3a

The team provides information to the patient and family/caregiver about evaluation and treatment procedures verbally and in writing.

Standard 3b

The team encourages patient and family/caregiver participation in the treatment process.

Standard 3c

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

Key aspects of family education and engagement include:

- Designating a member(s) to make initial contact with the patient and/or family and direct care providers, as appropriate for each patient.
- Accommodating patients' linguistic, cultural, and ethnic diversity, and ensuring that interpreters are available when needed.
- Providing educational information about cleft and craniofacial differences to patients, families, community-based providers, hospital staff and other stakeholders as needed.
- Assisting patients and families to understand, coordinate, and implement treatment plans.
- Communicating treatment recommendations to patients and families in both written and oral form.
- Providing prenatal education about potential feeding challenges and ongoing access to feeding and nutrition support.
- Working with patients and families to weigh treatment decisions against expected outcomes and related factors, such as facial growth, hearing, speech, dentition, as well as the psychosocial impact of treatment on the patient and family.
- Through shared decision-making, considering the potential psychological and other impacts of surgical procedures on the patient and family, especially if the child's treatment plan calls for multiple procedures or if it departs from routine practice.
- Prior to a surgical procedure, sharing relevant information about anesthesia and pre-and post-operative planning.
- As treatment progresses, providing updated information to families and repeating information delivery to ensure it is understood.
- Promoting sensitivity to the concerns of each caregiver(s), recognizing they may have different concerns.
- Assisting families in locating resources for financial assistance if needed.
- Facilitating formation of, and participation in support groups.
- Facilitating access to team care for adult patients where appropriate and feasible.

Quality Improvement

ACPA's Standards for Teams includes one quality improvement-related item:

Standard 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.

- Teams should have infrastructure in place to engage in regular self-assessment/audit of the process of delivering high quality of patient care (quality improvement) as well as the evaluation of clinically meaningful results (outcome measures).

- When appropriate, teams should use external peer review of their clinical outcome measures, as well as engage in benchmarking techniques to systematically compare selected measures (or groups of measures) across teams.
- Teams should conduct periodic surveys (ideally at pre-determined points in the treatment trajectory) of patient satisfaction.

Experience with Sufficient Numbers of Patients with Cleft and/or Craniofacial Differences

Standards for Teams offers guidance on the qualifications of team members: *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.*

- Each member of the team should have experience with, and exposure to a sufficient number of patients with CL/P and/or other craniofacial differences to maintain their clinical skills at the highest level.
- Teams should assist members in keeping current with their specialties by supporting and encouraging participation in continuing education activities and attendance at professional meetings.

4: Establishing Care with the Cleft/Craniofacial Team

Consistent with Principle III of optimal care for patients with craniofacial differences, the first evaluation of a child with a cleft or other craniofacial difference occurs shortly after birth, ideally within the first few days or weeks of life (Table 2). Patients with cleft and/or other craniofacial differences who receive optimal care during the neonatal period and infancy will likely interact with multiple health professionals, each of whom may conduct assessments and initiate a treatment plan in collaboration with other members of the team.

Given the complexity of information acquisition and establishment of care plans for infants with craniofacial differences, it is important to ensure that all aspects of care are fully addressed and coordinated in collaboration with the family. To achieve this goal, it is useful to categorize areas that should be evaluated during the neonatal period or during infancy. These include nutrition, feeding and growth; access to, and continuity of routine pediatric care; motor, cognitive, and social development; speech and language development; eustachian tube dysfunction and hearing; vision; hearing status; caregiver-child adaptation, caregiver skills, behavior management, and nurturance; the condition of the developing dentition and supporting tissues; early oral hygiene and prevention of caries; the child's overall health status as it pertains to surgical readiness and treatment modifications linked to information from genetic testing, associated or additional diagnoses, changes in family status or other factors that may impact care planning for the infant.

ACPA's Parameters address each of these aspects of care. This section focuses on some of the assessments and interventions that should be considered during the neonatal period and during infancy (Table 2). Subsequent evaluations and treatments should be conducted in a manner that addresses the needs of each patient based on collective decision-making between families and the interdisciplinary care team. (see Longitudinal Evaluation and Care).

TABLE 2: Health care during the neonatal period and infancy

NURSING CARE AND CARE COORDINATION	• Contact family shortly after referral to aid with feeding • Offer information in conjunction with the primary care provider (i.e. the pediatrician or family physician) • Ensure regular assessment of nutritional intake and weight gain during the first month of life • Maintain support for the family through telephone calls, office visits, and, when appropriate, referral for home health services • Reinforce information provided by the hospital at the time of discharge regarding: – Techniques of airway maintenance – Positioning of the infant – Nasogastric or gastrostomy tube care – Tracheostomy care – Respiratory monitoring • Assist the family in arranging evaluations with other members of the care team, as appropriate for the child or family
FEEDING, GROWTH AND NUTRITION SUPPORT	• Provide instruction and educational materials on feeding and other information such as the availability of special feeding devices • The caregiver's choice of feeding method should be supported if oral feeding has been evaluated for safety and the infant is able to meet his/her nutritional needs
AIRWAY MANAGEMENT	• If the infant is at risk for respiratory obstruction or sleep apnea, otolaryngological, surgical, and/or cardiopulmonary assessments should be performed. • Interventions may be indicated in infants with upper airway obstruction secondary to obstructive mandibular micrognathia. • Caregivers should receive education on sleep apnea.
EARS, HEARING, AND EUSTACHIAN TUBE DYSFUNCTION	• Newborns with cleft or craniofacial differences should receive an audiologic evaluation and appropriate follow-up. • Caretakers should receive education on symptoms of otologic disease, hearing loss.

DENTAL AND/OR ORTHODONTIC CARE	• Infant assessment by an appropriate specialist may include evaluations for:
	  – Neonatal teeth
	  – Treatment planning
	  – Presurgical molding
	  – Factors that may impact surgical management
	• Families should receive counseling on:
	  – Care of the oral cavity
	  – Prevention of dental caries
	  – Nursing bottle caries

GENETIC EVALUATION AND GENETIC COUNSELING	• Newborns should receive a complete physical examination.
	• Arrange for relevant evaluations as needed:
	  – Genetic evaluation and counseling
	  – Genetic testing
	  – Imaging studies
	  – Additional subspecialty evaluations

PSYCHOLOGICAL AND SOCIAL SUPPORT	• The family should receive assistance in identifying resources for emotional and financial support.[9] • The child's development should be monitored throughout the first year of life and referrals made as needed. • A culturally and linguistically appropriate psychosocial interview should be conducted or arranged.

SPEECH AND LANGUAGE SUPPORT	• Caregiver(s) should receive relevant education on:
	  – Typical speech and language development
	  – Speech and language impairments for which the child may be at risk
	  – How caregiver(s) can facilitate speech and language development
	• An assessment of prelinguistic speech-language development should be considered.

CLEFT/ CRANIOFACIAL SURGICAL MANAGEMENT	• Infants should be examined by a surgeon to discuss surgical options.

5: Longitudinal Evaluation and Care

Ongoing coordination among the interdisciplinary team, patient, and family enables longitudinal monitoring of progress, helps to rapidly identify emerging concerns, and greatly facilitates delivery of appropriate treatments. Even if the initial team visit occurs later in childhood or adulthood, optimizing care requires regular team evaluations to assess treatment outcomes and update care planning. The continuity of care that is provided by a qualified, interdisciplinary team working in tandem with patients and families enhances the longitudinal evaluation and treatment of patients of all ages. This care is focused on promoting health and well-being in a wide array of areas that are impacted by cleft and/or other craniofacial differences. This problem-based approach to care keeps the patient's goals at the center of care delivery and decision-making and it can be applied across the board to all disciplines that are represented on interdisciplinary cleft and craniofacial teams

Airway and Breathing

Upper aerodigestive tract pathology is prevalent in patients with cleft or other craniofacial differences[10–12] Upper airway obstruction may be caused by facial skeletal insufficiency, relative soft tissue excess, nasal and/or septal conditions, choanal stenosis/atresia, and laryngotracheal conditions.[13–15] Each of these conditions requires careful assessment and management tailored to the patient's anatomy and developmental stage.[16, 17] The complex needs of patients with significant airway compromise often requires close coordination among surgeons, pulmonologists, gastroenterologists, sleep medicine specialists, speech and language pathologists, and feeding specialists among others.

Ideally, airway assessment and care begin at birth and can extend into adulthood depending on the needs of the patient. Early otolaryngologic evaluation is important not only for responding to any immediate needs, but also for longer term care planning that may involve multiple members of the care team. In addition, anatomical differences may present challenges for perioperative airway management at the time of corrective surgical procedures such as cleft palate and orthognathic surgeries. In newborns, failure to thrive and feeding problems are often airway related and in older children, sleep disordered breathing and obstructive sleep apnea may contribute to failure to thrive and academic difficulties. Elements of care related to airway and breathing include:

- Based on history and clinical evaluation, sequential airway assessments to evaluate structural and functional causes of airway obstruction.
  - Airway assessments may include flexible and rigid endoscopy, radiographic studies such as CT and MRI scans, airflow studies, polysomnography, and

laboratory assessments such as capillary blood gas sampling.

- Airway management may include ablative procedures such as adenoidectomy, tonsillectomy, turbinate reduction, or tongue base surgery. Less common ablative procedures such as pyriform aperture drill out or choanal atresia surgery are sometimes indicated.
- Adenoidectomy may be recommended for nasal obstruction, inflammatory conditions such as rhinosinusitis or chronic otitis media with effusion. In children at risk for velopharyngeal dysfunction (e.g. children with a history of cleft palate), partial adenoidectomy may be beneficial to retain a portion of the adenoid to assist in velopharyngeal closure.
- Additional airway improvement may be achieved with corrective or augmentative interventions such as nasal and/or septal reconstruction and skeletal correction of retrusive mandible and/or maxilla.
- When indicated, laryngotracheal procedures such as tracheotomy and supraglottoplasty may be recommended for patients suffering from airway obstruction at the laryngeal level.
- The impact of secondary speech procedures (e.g., secondary palatoplasty, sphincter pharyngoplasty, pharyngeal flap) can alter airway anatomy potentially leading to higher risk of nasal obstruction, sleep apnea, and other airway obstructive symptoms.[18–20] These potential alterations must be considered before performing secondary speech surgeries.

Anesthesia

Patients undergoing most craniofacial surgeries, including CL/P surgeries, require general anesthesia (see Cleft Lip and Cleft Palate Surgery and Craniofacial, Midface and Mandibular Surgery). When anesthetics are performed in these patients, they require careful coordination between the surgical and anesthesiology teams. A detailed history and physical examination should be shared with the anesthesiology team to ensure that preoperative, intraoperative, and postoperative planning is appropriate for the patient's associated medical conditions.

Clefts of the lip and palate, craniosynostosis, and other craniofacial conditions can be associated with other medical conditions and/or syndromes, many of which have significant anesthetic implications, including congenital heart disease and difficult airway[21] (see Pediatric Health and Genetic Evaluation and Genetic Counseling). Additional anesthetic considerations for these procedures include potential complications of managing a shared airway. These include, but are not limited to, accidental extubation, potential disconnection, and endotracheal tube kinking. It is important for anesthesiologists who care for patients with CL/P and/or other craniofacial conditions to be experienced in airway management for these patients. An experienced anesthesiologist should be involved in airway management of younger patients because laryngoscopy is more difficult in infants than in older children and adults.

Preoperative Considerations

- A detailed history and physical examination should occur prior to the procedure with particular emphasis on evaluation for potential syndromes associated with CL/P or other craniofacial condition.[21]
- During the history, particular attention should be paid to comorbidities associated with each of these syndromes with an emphasis on anesthetic implications. For example, patients with Down Syndrome should be evaluated preoperatively for congenital heart disease and hypothyroidism because both conditions need to be optimized prior to an anesthetic.[22, 23]
- Patients with significant comorbidities should be considered for referral to higher acuity centers. For example, patients with congenital heart disease are at increased risk for perioperative complications, cardiac arrest, and mortality and therefore, should be managed in centers where anesthesiologists have experience caring for these patients.[24]
- ERAS (Enhanced Recovery After Anesthesia) protocols may be implemented to decrease hospital length of stay and narcotic use in appropriate patients.
- Patients should be evaluated for an acute respiratory illness because chronic rhinorrhea is common.[21]
  - If acute respiratory illness is present, a discussion between the surgery and anesthesiology teams should occur about when it is best to proceed.[21]
- Airway assessment should occur prior to any surgical procedure.[25, 26]
  - Interdisciplinary consultation for perioperative airway management should occur for patients who are at risk for difficult intubations because these patients are also at risk for difficult extubations (see Airway and Breathing).
  - Preoperative consultation with otolaryngology should be conducted for patients with a history of anatomic airway obstruction and/or prior difficult airway.
  - When feasible, a preoperative sleep study should be considered for select conditions[27] (see Sleep Health and Hygiene).
  - There should be particular attention to syndromic features and characteristics associated with a difficult airway such as Robin Sequence, bilateral cleft lip, midface hypoplasia, and micrognathia.[21]
  - Difficult intubation is relatively uncommon in patients with CL/P. Difficult laryngoscopy is associated with age < 6 months, site and degree of deformity, and micrognathia.[28]
- When feasible, surgical and dental procedures should be coordinated to minimize the number of hospitalizations, anesthetic exposures, and overall anesthetic duration.

Intraoperative Considerations

- If feasible, an anesthesiologist who is experienced in airway management of children with craniofacial conditions should be involved in the intraoperative care of pediatric cleft patients.[21]
- Premedication may be considered in younger children who have separation anxiety or older children with procedural anxiety.
- Sphenopalatine ganglion and suprazygomatic maxillary periopheral nerve blocks may be considered to decrease postoperative pain scores and opioid consumption.
- Inhalational induction may be considered in both anticipated difficult and anticipated normal airways in children.
- Intravenous induction may occur in older children or in children and adults with preexisting intravenous access.
- Maintenance of spontaneous ventilation may be considered during induction in patients with anticipated difficult airways.
- Use of difficult airway equipment including video laryngoscopy, supraglottic airway, rigid bronchoscopy and a fiberoptic bronchoscope may be considered.
- When a difficult airway is encountered or anticipated, the difficult airway algorithm should be followed.[29]
- Maintenance of anesthesia may be achieved by total intravenous anesthesia, volatile agents, or a combination of both.

Postoperative Considerations

- Patients should be monitored in the PACU or ICU after extubation until awake.[21]
- Patients of all ages with airway abnormalities have an increased incidence of obstructive sleep apnea. Anesthesia and pain medications can acutely worsen sleep apnea.

Patients with obstructive sleep apnea may require overnight observation in an age-appropriate unit with continuous pulse oximetry.[30, 31]

Dental Health

There is a high prevalence of congenital dental anomalies in patients with CL/P and other craniofacial differences.[32] These may include missing teeth, supernumerary teeth, ectopic or delayed eruption of teeth, variations of tooth size or shape, and enamel defects. It is for this reason that patients with craniofacial differences often require interdisciplinary dental services as part of a larger rehabilitative care plan. During the progression from infancy to adulthood, patients benefit from routine preventive and restorative dental care. They may also need additional, specialized dental services. Depending on the diagnosis and the patient's unique needs, these may include an orthodontist, oral and maxillofacial surgeon, periodontist, and prosthodontist. This section focuses primarily on routine dental care.

The need to emphasize oral hygiene in patients with craniofacial differences is supported by research showing high plaque indices, high prevalence of dental caries, and worse oral hygiene and periodontal status among these patients.[33–36] Dental health providers should

be familiar with risk factors that may increase the susceptibility of children with orofacial clefts to dental caries, gingivitis, and periodontal disease. These risk factors include enamel hypoplasia; supernumerary or severely ectopic incisors; a shallow vestibule in the anterior maxilla and tight upper lip due to scarring from primary lip surgery; orthodontic appliances; lack of supervision of a child's oral hygiene and diet; oral aversion causing fear of toothbrushing; oronasal fistulae with associated nasal secretions and food entrapment, and cognitive or motor delays that limit dexterity during toothbrushing.[37] Among children with special health care needs, those with craniofacial differences have twice as many unmet dental needs, with families facing frequent barriers to dental care such as cost and difficulty finding a dentist willing to treat their children.[38]

Caregiver(s) and health care providers should ensure that children with craniofacial differences can establish a dental home, ideally with a board-certified pediatric dentist. This is fundamental to helping patients achieve optimal oral health throughout childhood and adolescence, setting the stage for successful rehabilitative interventions.[39] However, because nomenclature for healthcare specialists can vary, families seeking a board-certified pediatric dentist may inadvertently choose a general dentist who accepts pediatric patients. It is for this reason that care teams should ensure families understand the importance of access to specialty trained dental professionals who recognize the complex nature of dental development in patients with craniofacial differences, often with medical comorbidities or behavioral management needs.[40, 41] These professionals have a critical role in oral care education, planning, coordination, and communication with caregivers and other health professionals.

- Evaluation with a dentist within the first few weeks of life is recommended for children with a craniofacial difference and any oral or dental concerns.[42] The presence of natal teeth, which are more prevalent in infants with orofacial clefts, can be ascertained and managed during the early evaluation.[43]
- Dental care should occur within six months of the eruption of the first tooth (and no later than twelve months of age) and continue regularly throughout life.[44–46] Ideally, the team should assist the family in identifying a pediatric dentist close to their home where the family can establish a dental home for the child and pursue routine dental care.[42]
- Early in infancy and if access is feasible, oral health evaluation and dental services should be provided by a pediatric dentist in coordination with other members of the interdisciplinary team.[42]
- Routine dental services every three to six months should include examinations, dental hygiene, caries control, preventive and restorative dentistry, management of space for dental eruption, and prosthetic dental treatment when needed.[42] Patients should be monitored closely to identify eruption disturbances, differences in the dentition, and periodontal disease.[42]
- Dentists should implement prevention measures to maintain the oral health of children with craniofacial differences, including: [35]

  - Guidance for caregivers on their child's increased risk of dental caries and periodontal disease.
  - Advising caregivers on the importance of limiting snacking and reducing consumption of sugars.
  - Instructing caregivers on performing oral hygiene of the infant as soon as the first tooth erupts and assisting older children during toothbrushing and flossing.
  - Ensuring competence with repeated instruction on toothbrushing and flossing among older children.
  - Educating caregivers on the importance of cleaning their child's teeth with fluoride toothpaste twice a day and supplying optimally fluoridated water to drink at home.
  - Application of fluoride varnish at the pediatrician's or dentist's office twice per year, beginning when the first tooth erupts.
  - Increasing the frequency of recall visits to the dentist for patients with inadequate home care, history of previous caries experience, or periodontal involvement.
  - Evaluating the dental and skeletal components of the child's dentition to determine if a malocclusion is developing for which orthodontic management may be recommended.
- Ensuring that the patient maintains good oral hygiene is important for the outcome of cleft-related surgeries (such as alveolar bone grafting) by preventing post-operative graft inflammation and infection.[47, 48]
- If presurgical infant orthopedics are under consideration, infant impressions, intraoral scanning, photographs, and facial imaging (3D soft tissue) can be useful to inform care planning.
- As the child ages, the pediatric dentist and care team may consider shifting routine dental care to a general dentist.[39] General dentists should be able to treat the complex dental needs of this population and manage the attendant medical and developmental comorbidities.[49]
- Maxillofacial and dental prosthetic rehabilitation may be required. Interventions may include an obturator to close palatal fistulae and speech appliances for nonsurgical treatment of velopharyngeal dysfunction.[35, 50]
- Edentulous areas may be restored with fixed or removable dental prostheses, and osseointegrated dental implants.[51]
- Disturbances of tooth form, enamel dysplasia and the substitution of adjacent teeth for missing teeth may require dental procedures to provide adequate size, shape, and function to the teeth.[52]

Ears, Eustachian Tube Dysfunction, Hearing, and Microtia

Patients with cleft and/or other craniofacial differences may have conditions that involve the outer, middle, and/or inner ear structures and patients with a cleft palate are at an increased risk for middle ear disease.[53–55] For these reasons, early otolaryngologic

evaluation is important not only for responding to any immediate needs, but also for longer term care planning that may involve multiple members of the care team.

Hearing loss is a feature of multiple craniofacial syndromes. Hearing loss can be conductive, relating to outer or middle ear malformations and middle ear dysfunction. Sensorineural hearing loss is also a feature of several craniofacial syndromes.[56] Hearing loss may be transient or permanent, and it can range in degree from mild to profound.[57] Hearing loss can have a detrimental effect on speech and language development, academic and vocational performance, and psychological and social well-being.[54, 58] Patients with cleft or other craniofacial differences therefore require routine audiology surveillance.[57, 59, 60]

Ears and Eustachian Tubes

- The ears should be examined on a regular basis beginning in the newborn period and continuing throughout childhood.[61, 62]
- Children undergoing myringotomies and placement of ventilation (pressure equalizing) tubes should have audiologic testing before and after tympanostomy tube placement and later at the discretion of the treating otolaryngologist.[63]
- Eustachian tube function should be evaluated on an ongoing basis to detect potential middle ear dysfunction and cholesteatoma.[64, 65]
- Early detection and treatment of chronic otitis media and otitis media with effusion is a core element of care.
- Treatment of middle ear disease may include systemic or topical antibiotics, insertion, or removal of tympanostomy tubes, tympanoplasty, removal of cholesteatoma, mastoidectomy, or ossicular reconstruction.

Hearing

- Audiological management should begin at birth (in the U.S.) in the form of universal hearing screening and results should be discussed with the family.[66] Any hearing loss should prompt collaborative treatment and management with an audiologist.
  - If the newborn did not pass the screen, a complete audiological diagnostic evaluation should be performed by three months of age.[53, 54, 66]
  - A complete diagnostic evaluation may be completed by nine months of age, regardless of whether the infant passed the newborn screen.[67]
  - Audiologic assessments may be obtained through several modalities.
  - These tests should be performed at the discretion of the examining audiologist and may be adjusted depending on age and developmental status of the patient.
  - Evaluations may include auditory brainstem response testing, or behavioral audiologic evaluation, such as visual reinforcement, conditioned play audiometry, or conventional audiometry.
  - Behavioral tests may be repeated periodically depending on the child's middle ear status and the any existing subjective concerns regarding hearing or speech development.[54, 58, 66]

- The timing of subsequent audiological follow-up evaluations may vary depending on the nature and severity of identified hearing loss, otologic management, caregiver concerns, speech and language concerns, and other potential risk factors for hearing loss.
  - Repeat testing through the first year of life should be considered,[68] and audiological follow up evaluations may continue through adulthood as necessary.[58, 66]
- If a patient with CL/P and/or other craniofacial difference presents with hearing loss of any type or degree, the treating audiologist will determine the schedule of audiological testing and candidacy for interventions such as hearing aids.
- At each audiology visit, behavioral and physiologic audiological testing often include:
  - Behavioral evaluations for pure tone air and bone conduction and speech audiometry.
  - Physiologic tests of acoustic immittance testing (tympanometry and acoustic reflexes) or otoacoustic emissions when appropriate.
- Management of hearing loss suspected to be caused by middle ear effusions should be coordinated with the child's medical team, including pediatrician or otolaryngologist, with input from the managing audiologist.[68]
  - Middle ear effusion often contributes to transient conductive hearing loss. However, if effusion and hearing loss persist and cannot be medically improved, hearing aids and referrals to early-intervention services may be considered.
- When a persistent hearing loss is identified, amplification (with use of conventional hearing aids, bone conduction hearing aids, cochlear implantation, and/or auditory training or frequency modulation (FM) systems) should be considered.[69]
- When a hearing loss occurs in the presence of microtia and aural atresia, either unilaterally or bilaterally, amplification should be strongly considered.[70]
  - Depending on the degree of loss, candidacy, and patient preference, a bone conduction hearing system may be considered.
- Once amplification has been provided, routine audiologic follow-up is necessary to monitor hearing status and the function of the amplification system.[69]
- For any child with hearing loss, a referral should be made to early intervention services and/or the child's school district, depending on the patient's age. Referrals may help determine appropriate services and support, such as recommended therapies, preferential classroom seating and/or use of an FM system.[66]
- Amplification with conventional hearing aids or bone conduction devices may be necessary to optimize hearing and facilitate communication. When medically appropriate, implantable hearing devices may be indicated.

Microtia

- Microtia and/or aural atresia reconstruction require close coordination among surgeons (otolaryngologists, craniofacial surgeons, neurosurgeons), anaplastologists, and audiology / aural rehabilitation professionals.
- Several management strategies for microtia treatment and reconstruction are

available when these interventions are indicated or desired by the patient and family. These procedures may be performed using autologous or alloplastic materials.[71, 72]

- The interdisciplinary team should work closely to identify and coordinate a treatment plan that considers the order of surgical procedures such that procedures that occur later in the treatment plan are not adversely impacted by ones that occur earlier. For example, the incision site and scarring from ear reconstruction can impact the feasibility and outcomes of future surgeries such as those on the jaw and to address hearing.
- Surgical treatment options for patients with microtia include surgical reconstruction of the external ear, auditory canal, and middle ear. Depending on the surgical method, microtia reconstruction may require a staged approach. The use of ear prostheses, which may be attached with adhesive or to osseointegrated implants, is an alternative to surgery.
- Osseointegrated implants may compromise future surgical ear reconstruction. This is also true for osseointegrated implants for hearing amplification. The choice between surgery and use of a prosthesis is a patient-specific choice that depends on an in-depth discussion with the interdisciplinary team regarding the benefits of both modalities.

Feeding, Growth, and Nutrition

Infants with CL/P and/or other craniofacial differences experience varying degrees of difficulty with feeding and growth. Infants with cleft lip only may be able to feed at the breast and with standard feeding systems, although some alterations in positioning or other modifications may be needed to provide appropriate feeding support. If challenges with feeding or growth are noted for these patients, guided alterations may be necessary. Infants with cleft palate and craniofacial differences are at high risk of feeding difficulties related to anatomic variations such as orofacial clefts, mandibular hypoplasia, and facial nerve palsy. Because infants with cleft palate cannot sustain the suction needed to maintain nutrition exclusively from the breast or standard bottle, they typically require specialized feeding systems to achieve adequate nutrition and hydration. A specialized assessment is needed to ensure that appropriate feeding systems and recommendations are provided for patients and their families. All patients with CL/P and/or craniofacial differences require ongoing attention to feeding and nutrition to ensure growth expectations are met and maintained.

The feeding care of infants with CL/P and/or craniofacial differences requires coordination and support. This support should be provided by one or more team-based feeding specialists who are experienced with the needs of this patient population, and these professionals can vary across teams (see Interdisciplinary Teams).[73] Team members who often provide feeding support include speech-language pathologists, dietitians, pediatricians and primary care providers, advanced practice providers, occupational therapists, nurses, and lactation counselors or consultants. If a team does not have a feeding specialist, the family should be referred to a professional who has the appropriate training and experience to provide high quality feeding support.[73]

The Prenatal Period

For families that receive a diagnosis of CL/P and/or a craniofacial difference in the prenatal period, prenatal consultations are critically important opportunities to receive information about challenges they may encounter with feeding. Because it is difficult to identify a cleft palate prenatally, if a cleft lip is visualized on prenatal ultrasound, providers should also educate and prepare families for the possibility of a cleft palate (see Interdisciplinary Teams).[74] Prior to the infant's birth, families should be provided with cleft-specific feeding systems and/or information for how to obtain these systems.[75] Breastfeeding challenges should be discussed and mothers interested in breastmilk feeding should be encouraged to secure a breast pump prior to the infant's arrival.[76–78]

Cleft teams often collaborate with providers in neonatal intensive care units and newborn nurseries to provide education and outreach services that ensure appropriate cleft feeding care is provided immediately following birth whether diagnosis is made prenatally or postnatally.

Feeding Support

Feeding specialists often use a combination of infant observation and caregiver reporting to develop an infant's feeding plan. Following initial assessment, close monitoring is needed throughout infancy to assess any additional feeding problems that may be related to developmental progression, surgical intervention, or underlying diagnosis.

Infants with cleft palate require cleft-specific feeding systems. Two categories of bottles are recommended for infants with a cleft palate: caregiver-assisted systems and infant-directed systems. Caregiver-assisted systems allow the caregiver to deliver the liquid to the infant by squeezing the bottle or nipple while infant-directed systems include a one-way flow valve that allows the infant to obtain liquids by manual compression alone. Because the parts, assembly, and use of these feeding systems vary, families should become familiar with the manufacturer's instructions and receive additional training from the feeding specialist. This training should include:[79]

- Observation and hands-on experience
- Written materials in the family's primary language
- Sanitation and cleaning instructions

Accessibility and feasibility of using specific feeding systems may vary by location, so teams should be aware of the products available in their area and able to train families on their use.[80, 81]

Exclusive, direct breastfeeding is extremely challenging for infants with cleft palate. Families should receive education and appropriate guidance on these challenges.[82] If breast milk provision is desired, mothers should be supported to pump and provide breast milk in an appropriate bottle.[76, 83] Non-nutritive opportunities at breast may be possible for mother-infant bonding and to stimulate breast milk supply. Families should be encouraged to work with their cleft feeding professionals to come up with a safe and optimal feeding plan to best meet the needs of the infant.

Feedings should be:[84]

- Reciprocal with the infant dictating his/her needs and the feeder providing appropriate support
- 30 minutes or less to reduce the baby's effort and caloric expenditure
- Offered between breaks to allow for optimal participation and to facilitate hunger

Feeders should be trained to observe the infant's cues indicating the need for alterations in the feeding process, adjustments to the feeding system, and changes in positioning.[78]

Feeding and Swallowing Challenges

If challenges with feeding and/or swallowing are noted and are unable to be managed with standard supports (e.g. nipple flow alteration, bottle change, positional change, etc.), additional referrals or assessments may be indicated. This is particularly important for infants in this population as additional diagnoses or syndromes may be present. Referrals should be determined based on the infant's symptoms. For example, an infant with symptoms suggestive of dysphagia may require an instrumental swallowing assessment.[85]

Eating and Drinking Skills

Cleft teams should provide education and support to families during developmental feeding transitions, such as food and cup introduction.[78, 84] Most infants with clefts and other craniofacial differences are able to follow the American Academy of Pediatrics timetable for solid food introduction.[83] In these cases, families should be:[78]

- Encouraged to use supportive seating systems, infant spoons, and appropriate food textures
- Provided with education that emphasizes positive introduction to solid food with nutritional value rather than significant volume consumption
- Counseled about unanticipated responses such as nasal regurgitation

Families should be encouraged to use cups based on the infant's ability and the team's guidelines. For infants with cleft palate, free-flowing cups are typically necessary, and use of small cups can begin as early as six months of age and continue throughout infancy.

Peri-operative Feeding Considerations

Although specific protocols may vary across institutions and teams, peri-operative feeding goals should mimic standard feeding recommendations as much as possible to ensure adequate eating and drinking skills are introduced and maintained.[84] Teams should consider potential post-operative feeding restrictions and educate and support families through these alterations.[86] For example, post-operative restrictions may involve exclusive provision of pureed solids or a change in drinking system. Families should be educated on these changes before surgery to allow time for the infant to become familiar with the new feeding system.[84] As post-operative restrictions remain inconsistent across teams, additional guidance related to feeding care should be provided by the treating

team prior to the intervention.[87] Teams may also consider providing education following the post-operative period, after surgical clearance, for the introduction of straws or other suction-based feeding systems to ensure a smooth process. These and other considerations should be covered by team members as part of Pre- and Post-Surgical Support.

Nutrition

Families should be educated about the need to use and provide clean water when offering formula and cleaning feeding supplies.[88] During infancy, there should also be discussion about how families are preparing the milk or formula to ensure proper measurements are used given the infant's caloric needs.[89] During discussions with the caregivers, providers should inquire about typical foods and liquids that are being offered to the infant.[90] Safer or healthier options should be discussed, as warranted.[91, 92] Providers should also make sure that families have adequate access to food and liquids with assistance provided by the team's social worker or other support staff member, when needed.[93, 94]

Growth

Close monitoring of growth metrics, including weight, length, and weight-for-length ratio, is essential in early infancy.[95, 96] Early and clear communication should be performed between the primary care provider, the family, and the cleft and/or craniofacial team. All providers should use the appropriate growth chart given the infant's age and prematurity status. Specific growth charts exist for some genetic conditions (e.g. 22q11.2 deletion syndrome).

The initial goal following birth is the return to birth weight by two weeks of age.[95, 96] If this milestone is not met, providers should evaluate whether alterations to the feeding and nutrition plan are needed to ensure optimal growth trajectories are established. Additional appointments may be needed with the team or the primary care provider during this critical time to monitor nutrition and growth. Measurement standards (i.e. naked weight) should remain the same, ideally using the same scale, for consistency. If expected growth metrics are not being met throughout infancy or childhood, additional subspecialty consultation (e.g. gastroenterology, endocrinology or genetics) may be needed for further assessment.

Genetic Evaluation and Genetic Counseling

Craniofacial differences are among the most common human congenital conditions. Among individuals with these conditions, the most common are orofacial clefting, craniosynostosis, and branchial arch anomalies. Some conditions have a known genetic etiology, such as 22q11.2 deletion syndrome, Van der Woude syndrome, Treacher Collins syndrome and Crouzon syndrome.[97, 98] With advances in genetic testing and identification of more genes associated with cleft and craniofacial conditions, recent data demonstrate a higher percentage of patients with craniosynostosis or CL/P being diagnosed with an underlying genetic etiology.[99, 100] A comprehensive genetic evaluation conducted by a clinical geneticist teamed with a genetic counselor can be beneficial in managing individuals born

with these conditions.[101–103] This is supported by well-established benefits of care models in which geneticists are embedded in interdisciplinary teams.[104–106]

Services provided by the genetics team include:

- Comprehensive clinical evaluation
  - Complete medical history.
  - A three-generation family pedigree.
  - A detailed full body physical exam that includes other systems outside the craniofacial region to evaluate for other congenital anomalies.
- Genetic testing that can determine underlying genetic etiology[107, 108]
  - Specific genetic testing may be ordered based on the patient's presentation (e.g. chromosomal microarray, targeted gene testing, comprehensive gene panels, whole exome sequencing, whole genome sequencing, etc.).
  - Pre and post genetic testing counseling and full consent for genetic testing.[109]
  - Discuss ethical and legal aspects of returning results from genetic testing.
- Genetic Counseling
  - Assist families in identifying support groups and community resources.
  - Provide genetic counseling including factual information, alleviating guilt, dispelling misperceptions, discussing decision making, and facilitating the coping process.
  - Discussion of recurrence risks.
  - Provide caregiver(s) of a child with a genetic condition with information about prenatal genetic tests that are available for future pregnancies as well as reproductive options.
- Comprehensive management and surveillance
  - Coordinate with other team members on potential medical or surgical risks related to the genetic diagnosis.[110–112]
  - Help guide patient management with screening tests and surveillance studies for associated conditions such as echocardiogram, renal ultrasound, ophthalmologic exams.
  - Recommend specialist referrals for children with genetic conditions associated with increased risk for atypical neurodevelopmental, cognitive, and behavioral outcomes.[113, 114]
  - Discuss with the family and team members the average clinical course and clinical variability that are associated with specific genetic conditions.
  - For patients with a cleft or other craniofacial differences, a comprehensive genetic evaluation can help determine if the patient has an isolated difference or if the condition is part of a syndrome. Syndromic forms of craniofacial differences can present with a higher risk for complications including in the immediate neonatal period. It is for this reason that confirming a genetic diagnosis can play an important role in surgical planning, determining if other specialist evaluations are needed, and assisting with family counseling about recurrence risks.[115–117]

Although any patient with a craniofacial difference may benefit from a consultation with a genetics provider, there are certain patient subgroups that may particularly benefit from genetic evaluation. These include patients:

- For whom it is unclear if an apparent craniofacial difference is isolated or syndromic and/or sporadic or familial.
- With one or more craniofacial difference or with associated medical problems such as pre- or postnatal growth delay, developmental delay, intellectual disability, autism spectrum disorder, sensorineural hearing loss, or seizures.
- Born with a craniofacial difference who have a positive family history of these conditions.
- With a known or recognized genetic diagnosis that may require yearly clinical genetic surveillance, molecular updates on a genetic variant, clinical management coordination based on the genetic diagnosis.
- Seen for the first time in the team at an older age.
- Whose families request genetic evaluation.

Some genetic syndromes involving craniofacial differences may not have apparent clinical manifestations that can be recognized in the first years of life. Accordingly, follow up genetic evaluations or initial evaluations later in life may be beneficial and take advantage of rapid improvements in genetic testing technologies.[118] As individuals with craniofacial conditions become young adults, they may also want to engage with a genetics provider to discuss their own risks of having children with similar features.

Orthodontic Health

Patients with craniofacial differences benefit from tailored orthodontic services that are delivered as part of a larger, interdisciplinary care plan that includes a dental home (see Dental Health).[42] If feasible, patients should receive orthodontic services from an orthodontist with experience in cleft and craniofacial care, or one who has completed a clinical fellowship in craniofacial and special-care orthodontics.[119, 120] These professionals often work as members of a cleft and craniofacial team, and they are referred to as the team orthodontist.

Prenatal counseling from a team orthodontist can be useful if the family has received a diagnosis of CL/P and/or other craniofacial difference that affects the dental occlusion or jaw relationships. If indicated, counseling should review the rationale for infant pre-surgical orthopedics. These discussions should cover expected dental eruption and jaw growth at various developmental periods in the context of each child's craniofacial diagnosis.[121]

Starting within the first days of life, the team orthodontist monitors growth, position, and size of the skeletal and dental components, allowing for the determination of the optimal time for orthodontic intervention. Visits should occur at least once each year, and more often depending on the needs of the patient. The team orthodontist provides direct care and may also assist the family with referrals to a pediatric dentist, oral- maxillofacial surgeon, periodontist, and prosthodontist. Some families may receive care from a community

orthodontist who is located close to the family's home, thereby facilitating attendance at appointments and access to urgent orthodontic care if needed. If a community-based orthodontist is involved in the patient's care, the team orthodontist and the community orthodontist should maintain close communication when appropriate, exchange updates on team recommendations, and discuss treatment timing, progress, and outcomes specific to each case.[122]

As the child grows, dental hygiene and behavioral traits may be assessed to determine timing for intervention. Active treatment is typically conducted in phases (infancy, primary dentition, transitional dentition, and permanent dentition), each with a specific objective.[123] Diagnoses and treatment planning require a variety of diagnostic records and a thorough clinical examination.[124] Maintenance of, and access to updated records allow for monitoring of craniofacial growth and development and results of ongoing treatment. When indicated, orthodontic treatment assists in preparing for cleft lip surgery, alveolar bone grafting, jaw surgery, and replacement of missing teeth.

Orthodontic services for patients with craniofacial differences are multifactorial and typically occur over many years. This section groups orthodontic care into three broad developmental periods: Infancy and Primary Dentition; Transitional Dentition and Adolescence; and Young Adulthood and Beyond. Although there is some overlap, these developmental periods highlight the importance of orthodontic care for patients with craniofacial differences throughout the life course.

Infancy and Primary Dentition

- If presurgical infant orthopedics are under consideration, infant impressions, intraoral scanning, photographs, and facial imaging (3D soft tissue) can be useful to inform care planning. On some teams, the orthodontist or the pediatric dentist may provide presurgical infant orthopedics.
- Dental care is necessary as primary dentition erupts. The orthodontist should ensure that the family has access to dental care in the context of a dental home.[42, 121] (see Dental Health).
- Before the primary dentition is fully established, the skeletal and dental components should be evaluated to determine if a malocclusion is present or developing.[42]
- Monitoring of dento-facial growth and development should continue throughout childhood and adolescence during visits with the team orthodontist.
- Early assessment of the severity of the maxillo-mandibular difference helps define achievable objectives and treatment modality.

Transitional Dentition and Adolescence

- When appropriate to diagnose and plan for orthodontic treatment, panoramic and cephalometric radiographs, photographs, and 3D imaging may be obtained.[120, 121] For patients at risk of developing a maxillary-mandibular discrepancy, properly occluded dental study models (or digital models) may be collected at appropriate intervals.

- If available, imaging with cone beam computed tomography can be useful to assess impacted teeth, root resorption, oral pathology, anatomy of the cleft, and bone graft outcomes.[125]
- Each stage of active orthodontic treatment should be discrete and followed by orthodontic retention and monitoring. Continuous, active orthodontic treatment from early mixed dentition to permanent dentition should be avoided.[121, 126]
- The orthodontist should engage in ongoing evaluation of dental hygiene and periodontal disease throughout active treatment and during growth monitoring and retention periods.[127, 128]
- Some children may benefit from dentofacial orthopedics using tooth-borne appliances like palatal expanders and headgear, or bone-anchored devices like bone plates and miniscrews.
- Palatal expansion should be titrated to the predicted antero-posterior relationship of the jaws. It should be accomplished differentially as needed with greater anterior expansion to avoid overexpansion in the posterior area.[129]
- In patients with severe skeletal discrepancies that are clearly surgical in nature, limiting orthopedic interventions with a low likelihood of success may reduce the overall burden of care.[123]
- In patients with alveolar clefts, orthodontic treatment may be needed to prepare for alveolar bone graft surgery (see Alveolar Bone Grafting). In these patients, the orthodontist should take diagnostic records, including radiographs of the cleft region and adjacent teeth, to determine optimal timing for alveolar bone graft and to plan for orthodontic treatment when necessary.[130]
- The orthodontist should consult with the surgeon to help determine the orthodontic needs prior to grafting, including maxillary expansion, limited tooth movement, fabrication of disocclusion devices in cases of traumatic occlusion, and surgical splints.[127, 131]
- Community-based orthodontists who are not on the patient's cleft team should coordinate care with the team orthodontist and/or surgeon to avoid preoperative treatment that may compromise graft outcome or risk tooth loss.[119] For example, maxillary expansion prior to grafting may not aim for crossbite correction but rather to improve the arch form and allow surgical access to the cleft site.[119, 132]
- After alveolar bone grafting procedures, dental radiographs (or cone beam computed tomography, when available) should be taken to assess bone graft outcomes (i.e., adequate bone support of teeth) before initiating or resuming orthodontic treatment.[133, 134] Functional stimulus of the grafted bone during orthodontic tooth movement can lead to better alveolar bone grafting outcomes.[135] Community orthodontists should also confirm bone graft outcome with the team orthodontist and/or surgeon.
- Orthodontic treatment in adolescence and retention may extend into adulthood.

Young Adulthood and Beyond

- Orthodontic treatment may be required in conjunction with surgical correction (i.e., osteotomies with or without distraction osteogenesis) for correction of a maxillo-mandibular discrepancy.
  - Collaboration and communication between the surgeon and orthodontist should precede all craniofacial surgical interventions to determine optimal timing as well as the goals of orthodontics and surgery.[126] This is particularly important because surgical intervention will have a direct impact on the dental occlusion and the growth and development of the dental and skeletal components.
- Individuals with congenitally missing teeth related to a history of cleft and/or craniofacial conditions may require fixed or removable prostheses or osseointegrated dental implants.
  - In planning orthodontic treatment for these patients, the orthodontist should collaborate with the prosthodontist to optimally position the teeth to allow for fabrication of well-supported, functional, and esthetic dental prostheses after completion of orthodontic treatment.[136]
- For growing patients with missing teeth who complete orthodontic treatment but are not developmentally ready for definitive prosthetic replacement of teeth, the orthodontist may work with the prosthodontist to fabricate provisional dental prostheses to preserve dental alignment and arch space for future rehabilitation.
  - Prostheses will also support a functional occlusion and ensure adequate smile esthetics.
  - During this time, the orthodontist should continue to monitor dento-skeletal growth.[137]
  - Once it is determined facial growth is complete, the orthodontist will refer the patient for prosthodontic rehabilitation.[138, 139]
- For some patients, a prosthetic obturator of palatal fistulae may be necessary. The orthodontist may work with the prosthodontist to fabricate a prosthetic obturator for patients who need this appliance.
- For some patients, a prosthetic "speech appliance" may be necessary to treat velopharyngeal dysfunction. The orthodontist may work with the speech language pathologist and the prosthodontist to fabricate the prostheses for patients who need one.
- When patients reach adulthood and after they complete orthodontic treatment, the cleft-craniofacial team should encourage patients to engage in periodic monitoring and continue to receive needed specialized care.[140, 141] (see Transition to Adult Care)

Pediatric Health

Pediatric care is fundamental to ensure that the health needs of children with cleft and/or craniofacial differences are identified and appropriately treated. Pediatric care ideally begins prenatally and continues until the patient's care is successfully transitioned to adult providers.[142] Primary pediatric care is often provided by a local healthcare provider

and includes well-child assessments and immunizations. Team-based pediatric care may be provided by pediatricians, nurses, advanced practice providers, and geneticists. The pediatric care provider partners with the patient, family, primary care provider, and other team members to optimize the patient's health and ensure that their craniofacial needs are addressed. Key goals of the team provider focusing on pediatric health include:

- Ensure that each child has a primary care provider.
- Identify the clinical diagnosis for the patient's health concern(s).
  - Accurate diagnoses are critical to ensure appropriate patient care.
  - Establishing a diagnosis may require genetic consultation and variable combinations of laboratory, imaging, and/or consultant evaluations (see Genetic Evaluation and Genetic Counseling).
- Provide the patient, family, community provider, and team providers with information regarding the patient's diagnosis.
  - Information may include etiology (if known), inheritance (recurrence risk for patient and family), and natural history (including associated health concerns).
- Monitor the patient's health status and initiate evaluation and treatment of health problems directly related to the specific craniofacial condition (e.g., cleft palate), diagnosis (e.g., 22q11.2DS), family history (e.g., biological parent with thrombosis), patient symptoms (e.g., sleep disordered breathing), and physical exam findings (e.g., murmur).
- Provide the patient, family, community provider, and team members with recommendations for age-specific health surveillance based on the patient's craniofacial diagnosis.
- Assess caregiver understanding of the child's health needs and address questions regarding their child's health issues.
- Evaluate the child's health prior to planned surgical procedures and provide recommendations regarding readiness for both surgical and nonsurgical interventions.
- Partner with the community healthcare providers to establish an individualized health surveillance plan.
- Provide the patient, family, community provider, and team members with diagnosis-specific health risk precautions, such as risks to the spine or from medications, or the potential for adrenal insufficiency.
- Partner with craniofacial team members and the community providers to advocate for appropriate community evaluations (e.g., Early Intervention Program), therapies, and support (e.g., individualized education program). (see Psychological and Social Support).
- Monitor children for growth failure, delayed development, abuse and neglect, and other significant health concerns.

When special needs are identified, referrals to appropriate specialists can be initiated in collaboration with the primary care provider.

Psychological and Social Support

Optimal outcomes for patients with craniofacial differences require periodic screening and assessment of the psychosocial needs of both the patient and family. The prevalence and impact of neurodevelopmental and social-emotional disorders in children with craniofacial differences support the need to screen for these conditions, and to follow-up with in-depth assessments and appropriate care for patients who exhibit signs or symptoms of these disorders.[143,-147] Psychosocial supports may be provided by one or more professionals such as social workers, psychologists, pediatricians, nurses, developmental-behavioral pediatricians, and psychiatrists. Ideally, these professionals will be part of the interdisciplinary cleft and/or craniofacial team. Excellent communication and care coordination are necessary for patients whose psychological and social service providers are not part of the care team.

Addressing the psychosocial needs of patients with craniofacial differences begins with clinic-based consultation and psychosocial screening, followed by standardized assessment of neurodevelopmental or social-emotional functioning for children who need it. Screening and needed assessments should begin in infancy and continue throughout young adulthood. It is important for team members to be sensitive to how treatment discussions can be perceived by children and teens; it is therefore important to use developmentally appropriate language that ensures the child understands the treatment plan. Team care should also include psychosocial support and transition of younger patients into adult craniofacial care.

Screening

- Psychosocial screening is a core component of cleft team care and may include interviews and screening questionnaires.
- Screening questionnaires should be age appropriate, empirically based, and administered and interpreted by qualified professionals.[141, 148, 149]
  - Craniofacial specific screening questionnaires may include the CLEFT-Q and Psychosocial Assessment Tool Craniofacial Version.[150, 151]
  - General screening questionnaires may include the Ages and Stages Questionnaire,[152] Pediatric Quality of Life (PedsQL),[153] PedsQL Family Impact Module,[154] PROMIS[155] measures of anxiety, depression, and experiences of stigma, and the Strengths and Difficulties Questionnaire.[156]
- When concerns are identified through psychosocial screening or consultation, appropriate referrals should be made for standardized assessment or treatment.

Assessment

- A standardized assessment of neurodevelopmental functioning is beneficial for patients whose screening results indicate these tests are needed.
- Standardized assessments should be performed by qualified professionals such as psychologists, developmental-behavioral pediatricians, or neuropsychologists.[144] These

professionals may be part of the craniofacial team or available via consultation and referral.

- Psychological or neuropsychological tests should be administered and interpreted by an appropriately licensed healthcare professional. Ideally, this person is familiar with craniofacial differences and related speech and hearing disorders.
  - Specific tests or questionnaires given as part of those evaluations are beyond the scope of the ACPA Parameters and should be deferred to an appropriately licensed healthcare professional.
  - Some assessments may also occur in the community through early intervention programs for children under 3 (e.g., Birth to 3, Early Steps, First Steps, Infant and Toddler Programs, Help Me Grow) or in the school setting for children older than 3 (e.g., evaluations for Individualized Education Programs).
- Standardized assessment of social-emotional functioning should be performed by one or more of the professionals listed above (e.g., social workers, psychologists, pediatricians, developmental-behavioral pediatricians, psychiatrists) or other qualified behavior or mental health professionals (e.g., professional counselors, clinical social workers, marriage and family therapists, psychiatric advanced practice providers).

Treatment

- Results of screening and standardized assessments help with care planning for psychological and social well-being.
- When possible, it is beneficial if psychosocial care is provided by a professional with knowledge of craniofacial conditions.
- Care plans may include behavioral health therapy, psychiatric medication management, school-based learning supports, and psychological or neuropsychological evaluation.
- As they mature, patients with craniofacial differences should be provided with information about their health condition (e.g. etiology, risk factors, risks and benefits of various treatments, heritability).
- Youth with craniofacial differences should be included in their psychosocial and other care planning including but not limited to surgical decision-making in a developmentally appropriate manner.[157, 158]

Monitoring and Social Engagement

- If assessment or treatment services are provided in the child's community, it is recommended that the team reviews and monitors these services on an ongoing basis.
- Psychosocial screening and interviews should be repeated periodically to monitor the patient's and family's emotional and behavioral adjustment; child behavior management skills; caregiver-child relationships; teasing or bullying about facial differences; fear and expectations about surgical procedures; emotional reaction to treatments or surgeries, and satisfaction with facial appearance.[159, 160]
- Psychosocial monitoring provides an opportunity to assess and address barriers that

may negatively impact outcomes such as family resource needs, caregiver supports, insurance, transportation, and family functioning.

- Families of children with craniofacial differences may benefit from contact with other families. Care team efforts to facilitate these contacts through child or caregiver support groups, networking, and other social opportunities may be beneficial for patients.

Sleep Health and Hygiene

Sleep-related breathing disorders (SRBD) are more common in children with CL/P and/or other craniofacial differences than the general population.[161, 162] Identifying and treating SRBD can inform surgical decision making, enhance quality of life and overall health, and reduce peri-operative risk.[163, 164] Craniofacial differences such as mandibular micrognathia, macroglossia, choanal stenosis or atresia, midface hypoplasia can contribute to obstructive sleep apnea syndrome (OSAS), and patients with these conditions may require additional assessment.

Closure of a hard palate cleft using vomer and/or nasal floor flaps inherently results in reducing the nasal airway on the affected side(s). It should be communicated to parents prior to cleft palate repair that reconstructive techniques used to repair palatal clefts often increase snoring during recovery and in some instances can lead to sleep disordered breathing or OSAS postoperatively.[165] Patients with syndromic craniosynostosis may have central nervous system (CNS) conditions, which are associated with central obstructive sleep apnea as well. Obesity is a risk factor for OSAS, and the growing prevalence of childhood obesity may exacerbate the impact of craniofacial differences on disordered breathing.

Infants with sleep disorders may exhibit subtle symptoms during sleep. Presenting findings in this age group may be poor weight gain and growth, poor color, and dysphagia. Beyond infancy, signs and symptoms of OSAS include snoring, noisy breathing, gasping, restless sleep, and arousals from sleep; daytime symptoms include changes in mood, attention, and alertness. Although this section focuses on SRBD, non-respiratory sleep disorders can also occur among patients with craniofacial differences, and they may amplify the impact of OSAS. These disorders include poor sleep hygiene, insufficient sleep, circadian rhythm disorders, insomnia, sweating, enuresis, ADHD, and movement disorders. Close collaboration between surgeons who perform interventions for sleep and other members of the care team is critical for effective treatment of sleep disorders among patients with craniofacial differences.

Screening and Diagnosis

- Diagnosis of SRBD begins with a careful history to delineate symptoms of abnormal breathing during sleep and evidence of inadequate sleep during wakefulness.
- Screening tools can be used to identify possible sleep disorders. "BEARS" is one such tool that contains questions about **B**edtime struggles, **E**xcessive daytime sleepiness, **A**wakenings at night, **R**egularity and duration of sleep and **S**noring.[166] Other tools include the Pediatric Sleep Questionnaire which includes a Sleep-related Breathing Disturbance Sub-scale.[149, 167]

- Physical exam is directed at features that may narrow the upper airway and identify potential sites of airway obstruction that may be amenable to surgical intervention.
- In select cases, drug-induced sleep endoscopy and/or upper airway imaging can help identify sites of airway collapse or obstruction. These tests can be useful for identifying targets for surgical intervention in complex or revision surgical cases, and also determine which cases may not benefit from surgical intervention.
- Polysomnography (PSG) provides an objective measurement of the respiratory pattern, gas exchange, and sleep architecture when symptoms and anatomy support a diagnosis of OSAS. PSG is the gold standard for documenting the type and severity of sleep-related breathing disorders and can be performed at any age. Although overnight studies in a sleep laboratory equipped to monitor infants and children are preferred, daytime studies are also useful for infants.

Surgical Management

- Craniofacial procedures like mandibular distraction osteogenesis or midface advancement that are helpful to restore craniofacial form may also help decrease upper airway resistance and ameliorate obstruction (see Craniofacial, Midface, and Mandibular Surgery).
- There is growing evidence that orthodontic palatal expansion (rapid maxillary expansion) may reduce the severity of upper airway obstruction.[168]
- Patients with cleft palate are at risk for velopharyngeal dysfunction, and surgical procedures aimed at addressing this problem can result in OSAS or worsen pre-existing OSAS.[169] The risk of precipitating or exacerbating obstructive airway symptoms should be considered when planning such procedures.
- Children with craniofacial differences may develop adenoidal and/or tonsillar hypertrophy, which can further narrow an already compromised airway and worsen OSAS. Tonsillectomy is often indicated in this circumstance.[151] Adenoidectomy may be relatively contraindicated in patients at risk of velopharyngeal dysfunction, including children with a history of a cleft palate. In such cases, medical management alone or a limited surgery with partial / choanal / superior adenoidectomy may be recommended.
- Peri-operative planning for any intervention requiring sedation or anesthesia should include consideration of the severity of any associated sleep-related breathing disorder.[155]
- Anesthesia and sedation may temporarily worsen sleep apnea. Untreated OSAS may exaggerate respiratory depression with narcotic analgesia. Arrangements for prolonged monitoring in the post-anesthesia unit or overnight observation in the hospital may be indicated for patients with severe OSAS (see Anesthesia).[170]
- Some instances of upper airway obstruction are only amenable to tracheostomy to by-pass the obstructed airway. Once airway anatomy has improved, readiness for decannulation may be determined by an airway surgeon through a number of means, which may include awaking capping trials and polysomnography with a capped tracheostomy.

- Craniosynostosis with Chiari malformation can result in abnormal central respiratory control leading to central and obstructive apnea, bradypnea, periodic breathing, and hypoventilation. Patients with these conditions should have a prompt neurosurgical evaluation.[171, 172]

Non-Surgical Management

- Medical management for obstructive sleep apnea, including healthy weight interventions, can supplement surgical therapies.
- When surgery is not possible, continuous or bi-level positive airway pressure therapy (CPAP or BIPAP) is the next line of therapy.[151]
- For patients with craniofacial differences who require CPAP or BPAP, referral to a pulmonary or sleep center is highly recommended for introduction to the therapy, mask fitting, education, and follow-up care.[151] A PSG with pressure titration is used to identify pressures needed to relieve upper airway obstruction.
- PAP efficacy can be monitored using data from the PAP unit. These data can also be used to modify the therapy and support adherence.

Speech and Language

Children with a history of cleft palate or a craniofacial difference are at increased risk of developing speech that may be difficult for others to understand, and/or speech that may sound different to that of other speakers.[173–175] Given the nature of their medical condition(s), the presence of velopharyngeal dysfunction may be a factor, resulting in 'nasal sounding speech' characterised by the presence of hypernasal resonance, audible nasal emission and/or nasal turbulence, as well as other related speech disorders. In infants and toddlers, early speech and language delay is also common.[176, 177]

Optimal outcomes for speech and language often require a combination of early speech-language intervention, speech therapy, and in some cases, additional surgery or prosthetic intervention targeting velopharyngeal function. A trained speech-language pathologist (SLP) with experience identifying and treating cleft or craniofacial-related communication difficulties is an essential part of an interdisciplinary cleft palate or craniofacial team.[178]

Management recommendations for the patient's speech and communication are included in the interdisciplinary team's coordinated treatment plan.[8] Collaboration between the patient's community and/or school-based SLP and team SLP is ideal to ensure that patients receive timely, appropriate, evidence-based speech and language intervention.[179, 180]

Assessment

Informal and formal perceptual assessments of a patient's speech and communication skills can:

- Establish the nature of each patient's difficulties
- Identify the extent to which each aspect of speech (for example, resonance, articulation etc.) is affected within a patient's current speech pattern.

- Determine the most appropriate intervention (e.g. speech therapy, surgical management, or prosthetic management) for each aspect of speech.
- Identify factors that contribute to the patient's speech difficulties and likelihood of successful intervention, including the patient's social skills and behaviour, any relevant co-morbidities, and the clinical findings from the patient's oral examination.
- Determine the overall impact of the speech difficulties on the patient.

This information informs the 'speech-language therapy' component of a patient's individualized team treatment plan and allows for recommendations for speech and communication intervention to be prioritized in conjunction with, and in consideration of, other aspects of the overall care plan.[181]

When indicated, patients may benefit from specialized investigations. These may include instrumental assessment procedures like nasometry[182] and/or pressure flow studies,[183, 184] and imaging assessment procedures such as multiview videofluoroscopy, nasopharyngoscopy[185] and magnetic resonance imaging.[186, 187] Imaging investigations inform clinical decision making and surgical planning, which should be done collaboratively between the team's SLP and surgeon(s).[188]

The timing and type of assessment depend on the patient's age and individual needs, and ideally occur often enough to:

- Ensure documentation of each patient's current communication skills.
- Document the patient's response to intervention(s) and treatment outcome(s).
- Develop recommendations for future intervention and treatment planning.

The assessment may contain non-standardized assessments, patient and/or caregiver reported measures, and more formal, structured perceptual speech assessments as appropriate to target the different components of each patient's communication. For example, formal expressive and receptive language assessments may be deferred to the community and/or school-based SLP who may be better situated to complete them because of ongoing interactions with the patient. Other evaluations, such as the detailed perceptual assessment of resonance, nasal emission and nasal turbulence, and comprehensive phonetic analysis of the patient's articulation and phonology should be performed by the team SLP.[168]

Specific parameters of care related to the assessments completed by the team SLP include:

- Management of speech and language difficulties in patients with a history of cleft palate or craniofacial differences begins with provision to caregiver(s) of information about the risks, characteristics, expected management and outcomes of communication difficulty in this population.[189] Information should be made available prenatally if applicable and at the time of the patient's first team presentation, and should ideally include the cost and availability of community and/or school-based SLP services.
- Assessment and counselling of early speech and language development may occur prior to cleft palate surgery. This aims to provide families with information and expectations about the nature of an infant's speech before and after surgery and provides an opportunity to describe and demonstrate strategies to encourage early verbal communication.

- Monitoring of early speech and language development may include reviewing home video or audio recordings of infants' communication attempts during play and other home activities. These recordings can be archived to create a longitudinal record of the patient's speech and language development that can be useful in care planning.
- SLP services should include regular evaluations of language development and speech intelligibility through early intervention services, the school system, and team visits depending on the needs of the child.
- The SLP should ensure that all assessment and treatment methods and techniques are appropriate for the patient's language(s) and/or dialect(s).
- Perceptual speech assessments for patients with a history of cleft palate or craniofacial difference are often conducted on a regular basis or as requested/recommended by the team SLP. Such assessments typically include evaluation of:
  - Speech sound production to classify the patient's speech sound substitutions, distortions, or omissions. Types of errors that may be identified include, but are not limited to, compensatory articulation errors, obligatory distortions, developmental errors, phonological patterns, and motor speech difficulties.
  - Resonance to determine the presence of hypernasality, hyponasality, cul-de-sac or mixed resonance.
  - Nasal air emission and/or nasal turbulence on pressure-sensitive consonants including consistency of presentation (consistent, inconsistent).
  - Differences in the patient's vocal quality.
  - Intelligibility/understandability of the patient's speech.
  - Acceptability of the patient's speech
  - The relationships between oral examination findings and the perceptual speech assessment results. These oral examination findings may include, but are not limited to, the presence of fistulae, dental/occlusal anomalies and confirmed or suspected submucous cleft palate.
  - Stimulability for improvement with speech therapy.
  - Need for further evaluation of velopharyngeal function via instrumental assessment.
- If any of the following are identified from the speech and language assessment, a referral should be made to a qualified, community and/or school-based SLP (including an early childhood intervention program that includes SLP services as appropriate):
  - Communication skills that are not age or developmentally appropriate
  - Articulation and/or phonological difficulties that are typically treated and amenable to speech therapy intervention
  - Compensatory, or maladaptive articulation difficulties that are commonly found in patients with a history of cleft palate, or a degree of velopharyngeal dysfunction
- For patients with suspected or documented velopharyngeal dysfunction, speech evaluations are necessary before and after any course of intervention.
  - These evaluations can help determine the patient's candidacy for further intervention for speech therapy, consideration of surgical intervention, or

consideration of prosthodontic management of the velopharyngeal mechanism for speech.

- For patients who are candidates for orthognathic surgery, pre-operative speech evaluations facilitate documentation of baseline speech performance and counselling about potential changes in speech following surgery.[190] Post-operative assessments capture changes in speech.
- If a voice difference such as dysphonic vocal quality is present, a referral should be made to an otolaryngologist for further evaluation. This is recommended prior to initiating voice therapy.

Intervention

The need for speech and/or language therapy for patients with a CL/P and/or other craniofacial difference, as well as the recommended nature of that therapy, should be based on results of a formal speech and language assessment and current best practices.[191, 192]

Specific parameters of care related to the speech therapy intervention as recommended by the cleft and craniofacial SLP include:

- The cleft and craniofacial SLP should actively collaborate with the community and/or school-based SLP to guide the development and implementation of an appropriate speech and language therapy treatment plan.
- The cleft and craniofacial SLP should ensure that the community and/or school-based SLP is aware of relevant assessment findings or other components of the patient's treatment plan that may impact the success of speech therapy intervention.
- For patients with compensatory or maladaptive speech difficulties or velopharyngeal dysfunction, the cleft and craniofacial SLP should educate, reinforce, and support the community and/or school-based SLP's understanding and implementation of principles of speech therapy intervention for patients with these difficulties.
- The cleft and craniofacial SLP should ensure that the community and/or school-based SLP and the patient's family are aware of the limitations of speech therapy in certain situations. While speech therapy can correct articulation placement errors including the compensatory maladaptive patterns that develop as a result of velopharyngeal dysfunction, as well as the specific speech patterns seen in cases of velopharyngeal mislearning, speech therapy will not correct the clinical manifestations of velopharyngeal dysfunction where the origin is structural or anatomical in nature i.e. resulting in hypernasal resonance and/or nasal emission and nasal turbulence. These patients should be considered for surgical or prosthetic intervention.
- Blowing exercises and other non-speech oral motor exercises are not effective in treating velopharyngeal dysfunction and should not be used.[193]

Surgery: Pre- and Post-Surgical Support

Once a surgical procedure is recommended and agreed upon with the patient and their family, clinicians on the team should provide information to the patient and their

family, as appropriate to the procedure and surgeon's preferences:

- Anticipated outcome(s)
- Pre- and postoperative feeding guidance
- Pain management
- Use of equipment, including immobilizers, if applicable
- Surgical site care
- Activity restrictions and/or positioning
- Cautionary constipation guidance
- Return to school guidance
- Patient and family adjustment
- Parameters for what symptoms should trigger contact with the surgeon's office
- Timing of post-op exam(s)

Instructions should be given in a manner that ensures understanding on the part of the family and other caregivers.

Surgery: Cleft Lip, Cleft Palate, and Related Surgeries

Surgical intervention for cleft lip and cleft palate is a fundamental element of a long-term, coordinated care plan for patients with craniofacial differences. Surgeons who perform these procedures may include plastic surgeons, otolaryngologist – head and neck surgeons, oral and maxillofacial surgeons, and/or other surgeons with expertise and specific fellowship training in cleft and craniofacial differences. These professionals may specialize in one or more surgical procedures, each of which may be associated with several techniques. The decision to pursue surgery and the choice of surgical technique should be individualized according to the needs and condition of each patient. A team's overall surgical protocol for longitudinal care from infancy to adulthood should aim to maximize form and function produced with each procedure while minimizing the impacts on growth and development. Given the burden of treatment on patients and families, secondary revision and repeat surgery should be minimized.

For patients and families that elect surgery, a timeline of potential procedures should be developed by the interdisciplinary team and presented to family and patients for consideration. Once a shared decision has been made regarding the timing of surgical intervention, a discussion of pre- and postoperative expectations may be facilitated by additional clinical staff, such as a physician assistant, nurse, or care coordinator (see Interdisciplinary Teams).

Surgery often begins with primary surgical closure of the cleft lip and/or cleft palate, as appropriate for each patient. Patients may also require secondary procedures involving the lip, nose, palate, or maxilla. The success of these interventions may depend on factors such as the severity of the underlying deformity, the surgeon's training and abilities, and the number of cases that the care team manages on a routine basis.[194, 195, 196] These procedures are often staged between infancy and adulthood. For some patients, several presurgical molding options are available (see Orthodontic Health).

Each team should have an established surveillance system and timeline after primary surgery to assess form and function throughout the course of facial growth. Surveillance should include ascertainment of complications, need for revisions, fistulas, patients' speech quality, and facial growth. This information should be used to ensure quality, safety, consistency across centers, and when relevant, subjected to specialty-specific peer review.

Surgical and dental procedures should be coordinated, and minimize the number of hospitalizations, anesthetic exposures, and the duration of each exposure to anesthesia. An expert and experienced anesthesiologist and peri-operative team should be involved in managing children who have cleft lip or cleft palate surgery. In cases where patients present with a high level of surgical or medical complexity, referral to higher acuity regional cleft centers of excellence should be made (see Anesthesia).

Cleft Lip Surgery

The goal of cleft lip surgery is to restore the function and anatomical features of the upper lip and nose. There are multiple protocols, and these vary across institutions. Protocols should provide the greatest restoration of form and functionality while limiting the number and duration of anesthetic exposures.

Primary lip surgery

- Primary lip surgery follows several principles:
  - Production of balanced lip form
  - Reconstruction of the orbicularis oris sphincter
  - Alignment of component contours (ie. cutaneous roll, vermilion, mucosa)
  - Consideration of all anatomic subunits of the nasolabial region
  - Establishing balanced and symmetric nasal base relationships
  - Optimizing facial growth, development, and overall facial harmony
- Primary surgery of the cleft lip is often initiated within the first six months of life for patients who are healthy, but care teams may determine that performing it later is appropriate for the needs of some patients.[197–202]
- For some patients, application of lip taping or presurgical infant orthopedics can improve the position of the maxillary alveolar segments or enhance nasolabial aesthetic outcomes prior to surgical closure of the cleft lip. (see Orthodontic Health).
- Depending on the severity of the cleft lip, primary rhinoplasty with or without limited septoplasty should be performed at the time of the primary cleft lip surgery to address nasal distortion.[203, 204] Surgery of the cleft lip nasal difference can be accomplished with limited additional incisions in or on the nose.
- The timing of, and indication for initial nasal surgery should be discussed with the patient and caregiver(s) so that the goals are understood, and expectations are realistic (see Pre- and Post-Surgical Support). The indication and type of nasal surgery technique should produce a valued change in appearance while minimizing the creation of scar within the nose.
- For severe clefts and/or when presurgical infant orthopedics have failed or are

not possible, a preliminary cleft lip adhesion may be performed in some patients preceding definitive cleft lip surgery.

Secondary lip and nose surgery

- Secondary cleft lip surgery may be indicated for persistent asymmetry, distortions of the skin and/or muscles, mucosal irregularities, scarring, or excess among other problems.
- Determination of the timing of these interventions may be driven by caregiver or patient concerns and the need for other procedure(s) that require anesthesia.
- Revisions should be avoided to preserve tissue, limit scarring, and reduce patient/family burden (emotional, psychosocial, and financial).

Cleft Palate Surgery

The goal of cleft palate surgery is to obtain normal function for speech and swallowing, as well as to optimize airway and dental facial relations. The repair of the cleft palate should optimize the velopharyngeal sphincter and minimize the effects on subsequent growth and dento-alveolar deformity.

Primary cleft palate surgery

- Primary surgery of cleft palate often occurs between 9-14 months of age. The timing should take into account the patient and/or family readiness (physically and emotionally). Ideally, the cleft palate should be closed by the age of 18 months. Closure of the palate before nine months of age has been described for select cases in select patient populations, but remains controversial.[205–207]
- Surgery on clefts involving the soft palate should include reconstruction of the sphincter function of the levator muscle.[208]
- Cleft palate surgery is a technically challenging procedure with risks of failure from traumatic tissue handling, devascularization of tissues, and inadequate tissue releases. Cleft palate surgery should not be undertaken by a surgeon unless they have expertise to conduct a reliable procedure with low risk of complication or failure.
- The airway can be compromised following cleft palate surgery and acute obstruction can lead to devastating consequences. Teams should have protocols in place to monitor patient airways following surgery and through the post-operative care. They should have the capability to reduce risks and manage acute obstruction if it occurs. Adjuncts and measures can include nasal airway devices, tongue stitches, anti-inflammatory medications (i.e. steroids) and careful selection analgesic and anesthetic agents (see Airway and Breathing).
- Acute bleeding can occur with cleft palate surgery. Surgeons should take measures to minimize bleeding during and after cleft palate procedures. Teams should monitor patients following surgery and be prepared to return to surgery rapidly should significant bleeding occur.
- Patients with submucous cleft palate may not need surgery. In these situations, patients should be monitored closely, with regular assessments of oronasal

regurgitation and resonance through early childhood to determine if surgical treatment is needed.[209]

  - The decision to proceed with surgery for these patients may be based on various factors but should be undertaken if there is velopharyngeal dysfunction which is characterized by persistent speech concerns such as hypernasality.[210, 211]

Secondary cleft palate surgery and surgery for velopharyngeal dysfunction

- If a fistula develops following primary surgery, surgical or prosthetic closure of palatal fistulae may be needed if the fistulae are symptomatic. Fistula treatment must be done very carefully because any surgery can increase the scar load for the child and affect the airways and overall dental facial growth. The chances of successful surgical closure of a fistula diminish with each attempt. Conditions should be optimized when undertaking surgery on a fistula. Additional local, regional, or distant tissue may be needed for closure of a fistula. Adjunctive devices/measures (i.e. bite blocks, palatal expansion) should be incorporated into the treatment plan as needed. Understanding and quantifying how symptomatic the fistula is, as well as the impact that fistula has on the patient is critical.
- Secondary cleft palate surgery and surgery for velopharyngeal dysfunction should be performed after evaluation—including imaging and/or endoscopic examination—of the velopharyngeal mechanism during speech.
- Evaluation by speech-language pathology specialists and input from other team members should be obtained before and after performing secondary palatal surgery for speech related concerns (see Speech and Language). The secondary surgery for velopharyngeal dysfunction will not correct the compensatory articulations such as glottal stops or nasal fricatives, and therefore follow-up speech therapy may be needed in some cases.
- Significant hypertrophy of the adenoids or tonsils should be assessed and addressed prior to surgery that addresses the velopharyngeal dysfunction.
- The patency of the nasal airway should be considered when planning either nasal reconstructive procedures or secondary velopharyngeal operations.
- Palatal and pharyngeal procedures to address speech-related concerns should be designed to limit airway obstruction.
  - Team assessment and input by speech-language pathology and airway specialists may be required in certain cases to mitigate these risks while still providing an improvement to speech (see Speech and Language and Airway and Breathing).

Alveolar Bone Grafting

- Surgery to unite the bony segments of the upper jaw may or may not be necessary based upon the initial cleft and previous treatment(s)
- Timing of bone grafting of the alveolar cleft should be determined by the stage of dental development and with the input of the treating orthodontist (see Orthodontic Health).
- Alveolar cleft surgery is common practice before the eruption of the permanent maxillary teeth in the region of the cleft. Grafting after the eruption of the adjacent

permanent maxillary canine, for example, can be associated with insufficient bone support, leading to decreased survival of teeth adjacent to the cleft and higher frequency of prosthetic replacements of teeth on the cleft side.
- For patients who have been lost to follow up or are late in presenting to the team for alveolar bone grafting, this procedure may take place after full eruption of the permanent teeth.
- Autogenous bone may be preferable when tooth movement through the graft is anticipated.[212]

Orthognathic Surgery

- Undergrowth of the maxilla may result in an anterior crossbite and flattening of the midface.
- If an anterior crossbite cannot be addressed by orthodontic correction or is significant, orthognathic surgery may be undertaken.
- While orthognathic surgery may alleviate some nasal airway obstruction, it may also exacerbate any existing velopharyngeal dysfunction. Assessment for velopharyngeal dysfunction prior to orthognathic surgery may help to predict patients at risk of developing or increasing hypernasality.
- Coordination between the orthognathic surgeon and orthodontist is strongly recommended.

Definitive Septorhinoplasty

- Optimization of the nasal airway may have benefits to oral hygiene (i.e. reducing mouth breathing) and reduce risks of obstructive sleep apnea (see Sleep Health and Hygiene and Airway and Breathing).
- Definitive septorhinoplasty should await skeletal maturity. If orthognathic surgery is indicated, septorhinoplasty is usually undertaken afterwards to avoid nasal changes that may occur with jaw surgery.
- Septorhinoplasty may involve addressing septal deviation and other measures to reduce nasal airway obstruction.
- Septorhinoplasty can also be undertaken to produce greater symmetry and facial balance.

Surgery: Craniofacial, Midface and Mandibular Surgery

Treatment for many types of craniofacial differences often requires staged surgical procedures at different periods of growth and development. These procedures can be categorized into three broad groups: cranial vault surgery, midface, and mandibular procedures. Surgeons who perform these procedures may include plastic surgeons, otolaryngologist – head and neck surgeons, oral and maxillofacial surgeons, neurosurgeons and/or other surgeons with expertise and specific fellowship training in craniofacial surgery.[213] For all procedures, the goal of surgery is to restore form and function, and this goal should be achieved in close partnership with an orthodontist with active experience treating patients with craniofacial differences.[214] Craniofacial and maxillofacial surgeons should

also communicate regularly with other members of the craniofacial team, as determined by the patient's needs. For example, surgeons who treat patients with, or at risk of sleep disordered breathing should consult with the team's otolaryngologist and a sleep medicine specialist (see Sleep Health and Hygiene). The surgical team should also ensure adequate communication with the community orthodontist if one is involved (see Orthodontic Health).

Surgical teams with sufficient numbers of relevant procedures and appropriate facilities for postoperative care have more favorable outcomes for patients with craniofacial differences.[215] In particular, appropriate intensive care facilities must be available for patients undergoing craniotomy or other procedures that might compromise the airway.

Minimizing morbidity and mortality from craniofacial operations entails thoughtful surgical indications that limit excessive anesthetic exposure, ideally with an experienced pediatric anesthesiologist present for procedures involving children (see Anesthesia). During maturation, the following should be monitored:

- Cranial and facial growth
- Overall development
- Neurological status
- Ocular function
- Speech and language
- Hearing
- Psychosocial adjustment

It is important that patients and families receive appropriate education and counseling about the potential risks and benefits of various surgical options and pathways, that patients are adequately prepared for each procedure, and that appropriate expectations are established (see Pre- and Post-Surgical Support).

Cranial Vault Surgery

Initial evaluation of an individual with a cranial vault condition should include a pertinent history and physical examination by team specialists with expertise in the diagnosis and management of craniosynostosis and other craniofacial conditions (e.g. genetics/dysmorphology, neurosurgery, ophthalmology, and craniofacial surgery).[216] This evaluation also applies to isolated orbitocranial differences of shape or position.

Timing and types of surgery for craniofacial differences depends on associated current and/or anticipated functional impairments, ophthalmologic concerns, elevation in intracranial pressure and patient/family preferences.[217–219] All surgical interventions require appropriate follow-up and monitoring. A multidisciplinary meeting was held in 2010 in Atlanta, Georgia, entitled "Craniosynostosis: Developing Parameters for Diagnosis, Treatment, and Management." The goal of this meeting, and the resulting report were specifically focused on parameters of care for individuals with craniosynostosis.[216]

Midface and Mandibular Surgery

Initial evaluation of midface and mandibular discrepancies includes assessment of skeletofacial proportions in vertical, sagittal, and transverse dimensions, dental occlusion, TMJ function, airway, and speech, with attention to the patient and caregiver concerns.

In adolescent patients with maxillary retrusion, orthopedic protraction with bone anchors may be considered, in collaboration with the orthodontist, to reduce the severity, or aid in correction of the jaw discrepancy[220] (see Orthodontic Health).

Although midface and mandibular surgery should be delayed until physical maturation is completed, earlier surgery may be indicated if there are serious concerns about a compromised airway, jaw function, speech, or psychosocial adjustment.[221]

For cases in which earlier surgeries are performed, the patient and family should receive counseling about the potential need for additional procedures to optimize outcomes and that these procedures may be more complicated due to earlier surgery (see Pre- and Post-Surgical Support).[222]

Orthognathic surgery (with or without distraction osteogenesis) is indicated when orthodontic treatment alone cannot achieve functional and/or acceptable aesthetic occlusion and facial harmony. Surgery should be timed to avoid adverse effects on subsequent facial growth and determined in consultation with the orthodontist and the team. Secondary procedures such as distraction osteogenesis may be needed to correct residual differences of the mandible, maxilla, orbits, zygoma, forehead, and nose and to correct problems with occlusion.

An orthodontic specialist should be consulted to establish orthodontic and surgical goals for cases in which surgical procedures may alter dental occlusion[223, 224] (see Orthodontic Health). Imaging with cone beam computed tomography should be available to the craniofacial and maxillofacial surgeons to assess impacted teeth, root resorption, oral pathology, anatomy of the cleft, and bone graft outcomes.[225] Impacted teeth can interfere with orthodontics, bone grafting, or orthognathic surgery. Evaluation and management of impacted teeth by an oral maxillofacial surgeon may be considered.

Collaboration and treatment planning between the surgeon and orthodontist should include:

- Frontal and profile facial images at rest and animation
- Orthopantomograms (panoramic radiographs) or facial CBCT
- Cephalometric analysis including prediction tracings
- Surgical planning with dental study models or with virtual methods

For patients at increased risk of post-operative velopharyngeal dysfunction (i.e., patients who have had cleft palate surgery undergoing maxillary advancement surgery), a speech evaluation should be done before and after surgery.[226] For patients at increased risk of OSA, a diagnostic work-up including polysomnography may be recommended (see Sleep Health and Hygiene). For patients with established OSA, the orthognathic surgeon and team may consider mandibular and/or maxillary advancement with or without distraction osteogenesis depending on the balance of risks and benefits to each patient.

- If mandibular ankylosis is present, surgical release should be considered and combined with a plan that includes postoperative physical therapy.[227]

- Temporomandibular joint replacement may be indicated in some patients with ankylosis, resorption, or severe degenerative changes.
- The child's ability to participate in postoperative therapy should be considered during treatment planning.

6: Transition to Adult Care

Although much of the care for patients with cleft or other craniofacial differences is provided by the time patients reach young adulthood, some patients require care in adulthood to address ongoing healthcare needs. These needs may relate to the effects of scarring, nasal deformity, malocclusion, missing or misaligned teeth, surgical or orthodontic relapse, hearing loss, or ongoing speech and resonance difficulties. Particularly for the replacement of missing teeth, prosthodontic treatment is typically deferred until skeletal facial growth is complete, and patients are young adults when they reach this stage. Adult patients with cleft or other craniofacial differences may also wish to have genetic counseling for their own health benefit and/or to learn more about what is known about inheritance patterns and/or genetic testing options. Psychosocial concerns related to living with a facial difference may impact postsecondary education, employment, and relationships.[228–230]

Some adults may be able to transition their care from a pediatric cleft or craniofacial team to an adult interdisciplinary team. However, for many adults these services may not be readily accessible or available because, for example, in the U.S., many interdisciplinary cleft and craniofacial teams are based in pediatric healthcare centers.[214] In addition to difficulties accessing adult providers with knowledge about cleft and craniofacial conditions and their treatment, gaps or delays in transition to adult care can occur due to lack of coordinated care and insufficient financial resources.[231]

Transition planning can facilitate seamless, coordinated care into adulthood. Ideally, transition planning begins through shared decision-making related to care during childhood and adolescence. Challenges in developing independence and autonomy about treatment decisions may have unfavorable implications for accessing and engaging in adult care.[232] Introduction of assigned transition workers to coordinate transition to adult care has been suggested with a focus on provision of individualized patient-centered care, access to medical history documentation, liaison with key health professionals (e.g., primary care providers, dental practitioners) and development of age-appropriate resources to facilitate the transition process.[217] Peer- and community-led interventions in conjunction with ongoing access to specialist medical care can have a positive impact on patients in the adult years.[215]

In some settings, it may be possible to continue coordinating care through the interdisciplinary team, while transitioning specific components of patient care to adult providers. That is, even if interventions such as orthodontic treatment, prosthodontic treatment, or further jaw or nasal surgery cannot be provided by cleft or craniofacial teams at the team's institution, the teams transition workers may be able to coordinate interdisciplinary assessment of the young adult's needs prior to these treatments. This coordination would involve liaising with community-based providers in the adult health care sector to ensure that the patient's needs are met. Therefore, it is recommended that interdisciplinary teams provide adult patients with continued opportunities for team care. This includes care coordination and assistance in identifying providers and locating resources for financial assistance to meet the individual needs of each adult.

7: Appendix

2024 Parameters of Care Update Task Force

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The following professionals supported the Task Force by contributing their time and expertise to the Parameters of Care update: Stephanie Kahntroff, MD, Lauren Madhoun, PhD, and Jessica Ogawa, MD.

Disciplines represented on the 2024 Parameters of Care Update: Anesthesiology, audiology; genetics; nursing; oral/maxillofacial surgery; orthodontics; otolaryngology; pediatrics; pediatric dentistry; plastic surgery; psychology; sleep medicine, speech-language pathology.

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