GUIDELINE STATEMENT
This guideline outlines the management of patients cleft lip and cleft palate as required by the Children’s Rehabilitative Services Program, Arizona Health Care Cost Containment System, State of Arizona.

PURPOSE
Clinical Practice Guidelines represent the minimum requirements for providing care for individuals with cleft lip/cleft palate. Care and treatment should be provided in a manner that includes adherence to and consistency with each of the following guidelines.

DEFINITIONS:
Children’s Rehabilitative Services (CRS): An AHCCCS program for children with certain diagnoses which provides services using an integrated family-centered, culturally competent, multi-specialty, interdisciplinary approach.

Multi-Specialty Interdisciplinary Clinic (MSIC): The Specialty Medical Home for the members with diagnoses as designated by the Arizona Administrative Code (AAC) R9-7-202 (R9-22-1303, 10-1-2013).
I. PROCEDURAL GUIDELINES for POLICY COMPLIANCE

A. CRS Enrollment:
Patients diagnosed with cleft lip/cleft palate and craniofacial anomalies must be enrolled at a Multispecialty Interdisciplinary Clinic (MSIC) site with a cleft lip/cleft palate and craniofacial anomalies clinic.

B. Interdisciplinary Team Membership:
The following team members must be available to attend clinics and team conferences, review patient information, determine the need to see the patients at a MSIC site and be available for inpatient consultation or coordinate care with inpatient staff at CRS contracted hospitals. It may not be necessary for each member to see the patient at each visit. One team member can fill more than one role, if properly trained.

- Audiologist
- Child Life Specialist
- Child Psychologist
- CRS Member / Caregiver
- Dentist
- Educator
- Genetic Counselor (optional)
- Geneticist
- Nutritionist
- Oral and Maxillofacial Surgeon
- Orthodontist
- Otolaryngologist
- PCP (invited)
- Pediatrician
- Plastic Surgeon
- RN Nurse Coordinator
- Social Worker
- Speech Therapist

C. Consultative Personnel:
The clinic must have access for consultation to specialists as identified by the Team.

D. Outreach Clinics:
Outreach Clinics are designed to provide a limited specific set of services including evaluation, monitoring and treatment in settings closer to the family than a clinic. Major treatment plan changes must be communicated to the clinic. Members with cleft lip/cleft palate and craniofacial anomalies may be seen in related specialty field clinics such as plastic surgery or nutrition clinics. Field clinic records must be provided to the MSIC

E. Community-Based Services:
Community-based services means all local services including provider agencies, schools, private physician offices, hospitals, and/or any other local setting. The following community based services may be provided from a community-based setting:

- Lab Service
- Pharmacy Services
- Speech Therapy
- General Dentistry – the dental services associated with cleft lip / cleft palate and craniofacial anomalies are specialized; they need to be provided with involvement of the Interdisciplinary Team.

F. Facilities and Services:
- Access to the pharmacy
- Age-appropriate setting for all patients
- Child Life Services
- Defined age-appropriate services: ie – Pediatrics, Adolescent Medicine, and/or Internal Medicine
- Equipment and expertise to measure height and weight
- General Dentistry – oral and maxillofacial Surgery, Orthodontic, and Prosthodontic Pediatric services available
- Identified clinic area for outpatient services
- Pediatric and/or Adult intensive Care Units appropriate for the age and complexity of the medical condition, as determined by the surgeon with medical consultation as needed.
- Physical Therapy
- Social Work Department
- X-ray services

G. Team/Staff Meetings:
Team and staff meetings will be held based on the age of the patient and their diagnosis. At a minimum, the following will occur:

1. Interdisciplinary Team Meetings - Evaluate patient at regularly scheduled intervals, the frequency and specific content of those evaluations being determined by the condition and needs of the patient and family. Hold regularly scheduled face-to-face meetings for discussion of findings, treatment planning, and recommendations for each patient. Develop a longitudinal treatment plan for each patient that is modified as necessitated by craniofacial growth and development, treatment outcomes, and therapeutic advances. CRS sites are encouraged to perform periodic chart reviews with documentation to ensure that all patients are reviewed and updated appropriately, according to their underlying condition.

2. Staff meetings once a year to focus on issues of clinic patient care and clinic administration.

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<th>Interdisciplinary Team Members</th>
<th>Interdisciplinary Team Members Available During Specialty Clinics As Needed</th>
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H. Lead Physician Specialists:
Qualifications: The Lead Physician Specialist should be a Team Member with experience and expertise in serving members with cleft lip/cleft palate and craniofacial anomalies.

II. GUIDELINES FOR PATIENT SERVICES, EVALUATION, AND MONITORING FOR CLEFT LIP/CLEFT PALATE
The purpose of these guidelines is to promote a uniform level of care at CRS Clinics for members with cleft lip/cleft palate and craniofacial anomalies and to provide a general framework for excellence in patient care. Their relevance to specific situations will depend on individual variations in clinical course and professional judgment, growth and development, and treatment techniques. In addition, this document should serve as an outline to assess programs, secure resources needed to enhance patient care and education, and guide the future development of treatments for patients with cleft lip/cleft palate and craniofacial anomalies.

A. Diagnosis and Treatment:

Goal: To provide accurate and timely diagnosis of patients with cleft lip/cleft palate and craniofacial anomalies

Goal: To habituate the patient through appropriately-times multidisciplinary interventions and monitor treatment progress and provide proactive treatment as appropriate.

Infancy:
- Audiology screening and followup
- Psychology-screening for patient and family adjustment
- Consultation with Pediatrician (Comprehensive Assessment Clinic)
- Consultation with Geneticist
- Consultation with Plastic Surgeon
- Contact made with Craniofacial Team Coordinator
- Contact made by Social Services
- Contact with other specialties as necessary
- Evaluation by Speech Therapist for feeding therapy
- Follow-up with pediatrician (Comprehensive Assessment Clinic)
- Orthodontics for pre-surgical molding of cleft lip and nosepalatal control device if required
- Pediatrician / PCP follow-up
- Repair cleft lip and nasal region
- Repair cleft palate, if appropriate – age 9-12 months/ concurrent PE tube placement if needed
- Social Services follow-up
- Evaluate speech and feeding post-surgery

Age 12 to 18 months:
- Cleft palate repair, when determined necessary
- Contact with other specialties, as necessary
- Behavioral Health screening as warranted
- Developmental Screening
- Pediatric dentist for oral examination, preventive education/procedures, speech/language evaluation
- PE Tube placement or evaluation and therapy as indicated
- Speech/language evaluation
Age 2-3 years:
- Full speech and language evaluation and therapy as indicated

Age 3 to 6 years:
- Contact with other specialties, as necessary
- Evaluation for VPI (velopharyngeal incompetence)
- Orthodontic evaluation with imaging, treatment as indicated
- Orthodontia-dental/facial orthodontia treatment initiation
- Screening for developmental and special education needs and referral, as appropriate
- Surgical procedures as indicated
- Behavioral Health- preschool readiness assessment

Age 6 to 9 years:
- Contact with other specialties, as necessary
- Orthodontic evaluation and treatment as indicated
- Behavioral Health screening for academic, social, and behavioral functioning. Therapy as indicated
- Screening for self esteem, teasing issues, and referral to psychology as needed
- Bone grafting of alveolar cleft/nasal revision as necessary
- Speech evaluation after surgery if grafting is performed

Age 9 to 11 years:
- Bone grafting of alveolar cleft
- Contact with other specialties as necessary
- Orthodontics treatment as indicated
- Speech evaluation and therapy as indicated
- Behavioral Health screening for academic, social, and behavioral functioning. Therapy as indicated

Age 11 to 18 years:
- Contact with other specialties, as necessary
- Lip revision / rhinoplasty
- Orthodontic treatment
- Orthognathic surgical procedures with post-op evaluation of VP function and articulation by Speech Pathologist
- Prosthodontics dentistry
- Behavioral Health screening for academic, social, and behavioral functioning. Therapy as indicated

Children Entering System at Older Ages:
- For patients enrolled in CRS after early childhood, the treatment parameters will be modified as appropriate for the patient's individual needs.

B. Transition Planning:

Planning for transition to adulthood should begin at age 14 years and continue until age 21 years.

C. Ongoing Patient Evaluation and Monitoring:
Goal: To anticipate and treat psychosocial problems and management of the condition

Psychosocial support with periodic assessment of patient and family needs. This can be performed by various specialists with referrals as indicated.

References:


