Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate

Basic Team

The special care needs of the child with cleft lip and/or palate (CLP) are met best by an interdisciplinary team of specialists who work in collaboration with the child, the child's parents, and the primary care health professional. The craniofacial team coordinator, if desired, can assist in the coordination of special services that these children require.

A CLP team typically consists of a plastic or reconstructive surgeon, an otolaryngologist, a nurse, an orthodontist, a dentist, an oral surgeon, a speech-language pathologist, a medical social worker, and an audiologist. Furthermore, consultation with or ready availability of the following disciplines is desirable: a genetic counselor, a medical geneticist, a developmental pediatrician, a radiologist, a prosthodontist, a dental hygienist, a psychologist, a physical therapist, and an occupational therapist.

Initial Evaluation

The optimal time for the first evaluation is at or shortly after birth; however, referral for team evaluation and management can be considered for individuals of any age. When the diagnosis has been made prior to delivery, prenatal counseling should be made available. The critical issues for the young infant with CLP are feeding and nutrition, initial surgical correction of the cleft, and pre- and postoperative support of the child and the family. The responsibilites of the primary care physician are to refer to the craniofacial disorders team (the team members initially involved are the plastic or reconstructive surgeon, the feeding specialist, the nurse, and the speech-language pathologist); identify associated defects; closely monitor growth and nutrition; and determine the need for other referrals (e.g., to the medical geneticist).

Frequency of Visits

The frequency and timing of visits to the specialty team are dependent on the child's needs and overall status. In general, the team evaluates the infant or toddler and the family at least twice yearly, and then yearly or as needed after the toddler years. The timing of the usual surgeries for children with CLP is as follows:

Surgical procedure	Age for completion
Lip adhesion	1–2 days
Initial lip repair	3–10 weeks
Palate repair	6–18 months
Pharyngeal flap and/or pharyngoplasty, if needed	2–7 years
Lip and/or nasal revision	4–6 years
Alveolar bone grafting	8–12 years
Cleft nasoseptal reconstruction	15–16 years
Orthognathic surgery	15 years or older

The primary care office monitors growth and nutrition, developmental and school progress, and middle-ear function; identifies associated medical problems; assists the family with care coordination; and provides ongoing child and family support and education in conjunction with the CLP team. The child's progress is reviewed at least annually (more frequently for younger children), and an office management plan is updated at that time.

The Physician's Guide to Caring for Children with Disabilities and Chronic Conditions, edited by Robert E. Nickel and Larry W. Desch,

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The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–1 month	*Feeding/Nutrition/Risk for Dehydration*	Growth parameters, evaluation by feeding specialist as needed	Feeding specialist, nutritionist
	Cause of the Cleft Lip and/or Palate (CLP)	Evaluation for minor anomalies, craniofacial dysmorphology screen	Developmental pediatrician (DPed), medical geneticist as needed
	Evaluation for Associated Congenital Defects	Blood chromosomes, other tests as needed Cranial ultrasonography (US) or computed tomography (CT) scan, echocardiogram, other tests as needed	DPed and/or medical geneticist
	Closure of the Lip	Pre- and postoperative care	Plastic or reconstructive surgeon, CLP team
	Hearing Status/Risk for Middle-Ear Effusion and Infection	Schedule neonatal hearing examination with auditory brainstem screening (ALGO) or otoacoustic emissions (OAEs), prophylactic bilateral myringotomies and ventilation tube placement	Audiologist, otolaryngologist (ENT)
	Risk for Airway Obstruction (*e.g., Pierre Robin sequence*) *or Aspiration* (*e.g., laryngeal cleft*)	Detailed otolaryngologic examination, positioning, other interventions	ENT, plastic or reconstructive surgeon, DPed, nurse
	Need for Intraoral Prosthetic Appliance	Evaluation for bilateral and/or severe clefting	Plastic or reconstructive surgeon, dental specialist
	Parent Education/Anticipatory Guidance *Care Coordination/Family Support*	Initiate care notebook, provide educational materials and resource list; complete family interview using parent questionnaire (e.g., Family Needs Survey) or CLP psychosocial screening form as needed	Speech-language pathologist (SLP), ENT CLP team coordinator, medical social worker, DPed, referral to community health nurse as needed
1 month–5 years	*Growth/Nutrition* Oral motor dysfunction Gastroesophageal reflux (GER)	Growth parameters, diet record, evaluation by feeding specialist, workup for GER as needed	Nutritionist, feeding specialist, DPed as needed
	Initial Palate Repair (6–18 months of age) Pre- or postoperative support	Confirm that family is established with plastic or reconstructive surgeon	Plastic or reconstructive surgeon, nurse, SLP, other team members as needed
	Monitor Hearing Status/Middle-Ear Function	Audiologic testing at least annually or as needed	Audiologist, ENT as needed

Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate *(continued)*

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
1 month–5 years *(continued)*	*Dental Care* Prevention of dental caries	Review dental hygiene and potential dental issues (e.g., missing and supernumerary teeth)	Dentist
	Associated Medical Problems Visual problems or strabismus Seizures Craniosynostosis Associated congenital defects (e.g., heart or renal defects, hand or foot anomalies)	 Vision testing Electroencephalogram (EEG) Skull X rays, cranial computed tomography (CT) scan as needed Additional tests dependent on type and severity of associated problems	 Pediatric ophthalmologist Neurologist Neurosurgeon Cardiologist, orthopedist
	Speech-Language Progress Language delay Speech disorder (due to dental and anatomic differences) Voice quality and need for pharyngeal flap for velopharyngeal incompetence (2–7 years of age)	 Monitor language progress Assessment of velopharyngeal incompetence and voice quality	 SLP SLP, orthodontist, oral surgeon SLP, ENT, plastic or reconstructive surgeon as needed
	Developmental Progress/Need for Early Intervention (EI) or Early Childhood Special Education (ECSE) Services Speech-language delay Developmental delay	Developmental surveillance and screening Refer for eligibilty testing for EI services as needed	Referral to child development team as needed
	Family Support Services Respite care Parent group Community health nurse Advocacy Financial services (e.g., Supplemental Security Income [SSI])	Family interview, parent questionnaires (e.g., Family Needs Survey) Provide resource information (e.g., Cleft Palate Foundation) Care coordination	Medical social worker, referral to community health nurse, other community services as needed

Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate *(continued)*

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
1 month–5 years *(continued)*	*Anticipatory Guidance* Review individualized family service plan (IFSP) with family as needed Transition from preschool to kindergarten Risk for dental, orthognathic, or facial differences and their treatment Risk for behavior problems, low self-esteem Promote self-care and independence	Family interview, educational materials, resource information Teacher interview, school conference as needed	Primary care office in collaboration with CLP team
	Collaboration with Community Services Community health nurse Educational services	Comprehensive care coordination with regular exchange of written information (at least yearly) with other service providers	Primary care office in collaboration with CLP team
6–12 years (school-age)	*Dental Care* (e.g., missing or impacted teeth)	Full set of dental X rays	Dentist, oral surgeon
	Facial Differences Lip or nasal revision (ages 4–6 years)	Evaluation of facial aesthetics and function	Plastic or reconstructive surgeon
	Orthognathic Differences Alveolar bone grafting (ages 8–12 years)	Establish orthodontic care and, if indicated, oral surgical care	Orthodontist, oral surgeon
	Speech-Language Progress Increased risk for hypernasality as adenoidal tissue atrophies	Evaluation of speech-language skills, voice quality, and assessment of velopharyngeal incompetence as needed	SLP, ENT as needed
	School Progress Learning disabilities Mental retardation (if birth defect syndrome is present)	Regular exchange of information with school behavioral questionnaires; child, parent, and teacher interviews; school progress report; intellectual and achievement testing as needed	Referral to child development team or individual psychology appointment as needed Collaborate with school staff
	Social Skills Involvement in peer-group activities at school and in the community	Encourage participation in community services, social skills program at school as needed	Psychologist, behavioral specialist, school counselor as needed

Guidelines for the Care of Children and Adolescents with Cleft Lip and Palate *(continued)*

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
6–12 years (school-age) *(continued)*	*Anticipatory Guidance* Discuss diagnosis and management with the child Need for cleft nasoseptal reconstruction, orthognathic surgery Transition to middle school Recreation and leisure activities	Child and family interviews, provide educational materials and resource information Encourage participation in community recreation and leisure activities	Primary care office in collaboration with CLP team and school staff
13–21 years (adolescents and young adults)	*Cleft Nasoseptal Reconstruction* (ages 15–16 years)	Evaluation of airway and appearance of nose	Plastic or reconstructive surgeon and/or ENT
	Orthognathic Surgery for Class III Malocclusion (ages 15 years and older) Retrusive midface Prognathism	Evaluation of dentoskeletal facial balance and function	Oral surgeon, orthodontist
	Persisting Speech Differences Risk for velopharyngeal incompetence Continuing articulation difficulties Continuing vocal quality deviations	Monitor voice quality, assess velopharyngeal competence as needed	SLP, ENT as needed
	Anticipatory Guidance Review genetics and recurrence risk with adolescent and family Promote healthy behaviors (e.g., diet, exercise) Sexuality and high-risk behaviors (e.g., substance abuse) Transition to high school Career planning/higher education Transition to adult medical services	Adolescent and family interviews Teacher interview, school conference, review individualized education program (IEP) with family as needed Referral to gynecologist, mental health specialist as needed	Primary care office in collaboration with CLP team

Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate

This form will help you and your physician review current services and service needs. Please answer the questions about your current services on this page. Your physician will review your responses and complete the rest of the form.

Child's name _____ Today's date _____

Person completing the form _____

CURRENT SERVICES

1. Please list your/your child's current medications and any side effects.

2. What is your/your child's current school program?

   School name _____ Grade _____

   Teacher _____ Telephone _____

3. Do you/does your child receive any support services or other special programs at school (e.g., speech pathologist)? Please list.

4. Who is your/your child's surgeon? _____

   Date last seen _____

5. Who are your/your child's other medical and dental service providers?

   Dentist _____

   Orthodontist _____

   Plastic surgeon _____

   Otolaryngologist _____

   Speech-language pathologist _____

   Audiologist _____ Date hearing was last tested _____

   Any hearing concerns?

Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate *(continued)*

6. Who are your/your child's other community service providers?

   Community health nurse _____

   Other _____

7. Do you also receive services from a cleft lip and palate team of specialists?

   Contact person _____

   Location _____

8. Have you/has your child had any blood tests, radiologic (X-ray) examinations, or other procedures since your last visit? If yes, please describe.

9. Have you/has your child been hospitalized or received surgery since your last visit? If yes, describe.

10. Please note your/your child's accomplishments since your last visit. Consider activities at home, in your neighborhood, or at school, as well as success with treatments.

11. What goals (i.e., skills) would you/your child like to accomplish in the next year? Consider activities at home, in your neighborhood, or at school, as well as success with a treatment.

12. What questions or concerns would you like addressed today?

Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate

The Family and Physician Management Plan Summary should be completed at each annual review and more often as needed. It is intended to be used with the Guidelines for Care, which provide a more complete listing of clinical issues at different ages as well as recommended evaluations and treatments.

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
Family's Questions					
Cause of the Cleft Lip and/or Palate (CLP)					
Growth/Nutrition Feeding problems					
Surgical Checklist Initial lip repair Initial palate repair Lip or nasal revisions Myringotomy/tube placement Alveolar bone grafting Cleft septorhinoplasty Surgical improvement of velo-pharyngeal closure if indicated Orthognathic surgery Other					
Dental and Orthodontic Care					

Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate *(continued)*

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
Hearing Status/Middle-Ear Function					
Risk for Airway Obstruction					
Associated Medical Problems Visual problems or strabismus Seizures Craniosynostosis Other congenital defects					
Speech-Language Progress Need for speech-language therapy Poor speech intelligibility Voice quality (nasality)					
Developmental/School Progress Current school achievement Review individualized family services plan (IFSP) or individualized education program (IEP) with family					

Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate *(continued)*

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
Social Skills Involvement in peer-group activities at school and in the community					
Self-Care/Independence					
Family Support Services					
Anticipatory Guidance List issues discussed and materials provided					
Collaboration with Community Agencies School Community health nurse					

Family and Physician Management Plan Summary for Children and Adolescents with Cleft Lip and Palate *(continued)*

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
Comments					

Next update of the Management Plan Summary _____

Signature _____ Date _____
(Child and parent)

Signature _____ Date _____
(Health professional)

CRANIOFACIAL DISORDERS PSYCHOSOCIAL SCREENING FORM

Child's name _____ Age _____ Date of birth _____

Diagnosis _____ Today's date _____ Examiner _____

Surgical variables

Motivation for treatment _____

_____

_____

Understanding of risk-to-benefit ratio _____

_____

_____

Expectations of surgery _____

_____

_____

Number of prior surgeries _____

_____

_____

Psychosocial variables

Body image _____

_____

_____

Self-concept _____

_____

_____

CRANIOFACIAL DISORDERS PSYCHOSOCIAL SCREENING FORM *(continued)*

Emotional status _____

_____

_____

Social skills _____

_____

_____

Behavior problems _____

_____

_____

Family and social support

Parents' motivation for treatment _____

_____

_____

Parental relationship _____

_____

_____

Family climate _____

_____

_____

Family cohesion _____

_____

_____

CRANIOFACIAL DISORDERS PSYCHOSOCIAL SCREENING FORM *(continued)*

Available social support _____

_____

_____

Educational variables

Child's age _____ Grade _____ School placement _____ Special services? Yes _____ No _____

CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM

Child's name _____ Age_____ Date of birth _____

Diagnosis _____ Today's date _____ Examiner _____

Cranial deviations

Cranial size _____

Cranial shape _____

Hair growth pattern _____

Other _____

Craniomaxillofacial deviations

Craniofacial deviations _____

Ear structure, size, and position _____

CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM (*continued*)

Presence or absence of skin tags and pits _____

_____

_____

Size, shape, and function of nose, including nasal ala and columella _____

_____

_____

Philtrum _____

_____

_____

Lip intactness, shape, thickness, and function, including potential lip pits _____

_____

_____

Contour and intactness of alveolar process _____

_____

_____

Dentition _____

_____

_____

Dental occlusion _____

_____

_____

CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM (*continued)*

Contour and intactness of hard palate _____

_____

_____

Contour and intactness of soft palate _____

_____

_____

Appearance of face (e.g., malar eminences, midface) _____

_____

_____

Length, mobility, and symmetry of soft palate _____

_____

_____

Depth of oropharynx in relationship to soft palate _____

_____

_____

Other _____

_____

_____

Cranioorbital deviations

Eye structure, position, orientation, and function _____

_____

_____

CRANIOFACIAL DISORDERS DYSMORPHOLOGY SCREENING FORM (*continued*)

Other _____

_____

_____

Craniomandibular deviations

Tongue size, structure, and function _____

_____

_____

Size and symmetry of mandible _____

_____

_____

Other _____

_____

_____

Source: American Speech-Language-Hearing Association (1993).