

### Standard 3: Patient and Family/Caregiver Communication

To view examples of standard 3 documentation that Teams have submitted as evidence of compliance of the Standards for Cleft Palate and Craniofacial Teams, please visit: <http://www.acpa-cpf.org/standards-examples>

#### 3.1 The Team provides appropriate information to the patient and family/caregiver about evaluation and treatment procedures orally and in writing.

20. Who is responsible for providing information about patient evaluation and the recommended treatments to families and patients? How is the information communicated to them?

After the Team meeting, the patients and their families return for a meeting with the Team Director or Coordinator to review team recommendations and a written summary is provided. The summary focuses on specifics of the Care Plan but ample opportunity is provided for questions and discussion on any topic of concern during the 10-15 minute meeting. In addition, patients and families have had opportunity to ask questions of the Team members from each discipline during their earlier evaluation. We also encourage patients / families to call the Team staff with questions at any time. A comprehensive Team report is mailed to each patient/family within 2 to 4 weeks of the team meeting.

#### 3.2 The Team encourages patient and family/caregiver participation in the treatment process.

21. Describe how the family/caregiver has opportunities to play an active role in the decision-making process for the treatment plan.

A strong emphasis is placed on family-centered care in our clinic. Family-centered care is facilitated through building relationships of trust, devoting adequate time for each provider to spend time with the patients and their families, and making sure families have adequate information to make decisions regarding their child's care. We intentionally limit the number of patients we see in each clinic to approximately six per Team day so that there is optimal time for providers and patients/parents to interact. Families are given opportunities to play an active role in the treatment process in many ways, including the choice of their child's providers and the specific treatment option, which best suits their child when more than one option is acceptable. We also encourage the patients to become active in the decision-making process as young as possible. Patients and parents are viewed as members of the Team, with their opinion valued and respected equally. Beginning with prenatal consults, parents are given the names of 2-3 cleft surgeons on our Team to meet so that they can choose the surgeon that they feel is best for their family. The same is done when it is time to find an orthodontist and other specialists. Active participation is encouraged by giving the families multiple opportunities to ask questions on the day of the Team visit but also as they go home and consider the treatment options. At the start of each Team visit, the Team director meets with each family and asks both the patient and the parents what their goals are, if they have questions for the Team or if there are specific concerns at this time. The Team recommendations are presented as options to be considered within the context of the patient's and family's life rather than as a rigid prescription that must be followed. Patients and families are also encouraged to be active participants through discussion with their local community providers

regarding treatment options outlined in the Team report.

22. Describe how the patient is involved in the decision-making process for the treatment plan at an appropriate age.

Patients are involved in their care beginning as soon as possible. The Team director meets with the child and their parents before the start of each Team visit and explains to the child what the day will involve and explicitly asks the child if they have any questions or concerns. Both the director and the coordinator make it their goal to make sure young children know that the day is all about them. From a young age children are encouraged to ask questions. Each Team member sees patients on an individual basis to ensure the child is minimally intimidated and has more opportunities to interact with each provider. Providers talk directly to patients when at all possible. Transitioning to adult care is initiated during adolescence. Adolescents can be seen privately upon request. Questions regarding what they desire for treatment are addressed directly to them and decision-making is balanced.

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

23. Describe the process for informing families/caregivers of financial and insurance-related resources. These might include federal, state, and provincial regulations specifically governing the treatment of cleft/craniofacial anomalies. (e.g., insurance, state agencies, Public Law 94-142, 504s, and individual educational plans).

mandates insurance coverage for “congenital malformation” including “benefits for individuals age 19 up to the limiting age for coverage of the dependent are limited to inpatient or outpatient expenses arising from medical and dental treatment that was scheduled or initiated prior to the dependent turning age 25.”

The Cleft Palate and Craniofacial Clinic is also fortunate to be supported by generous benefactors who have created and continue to support a fund, which provides coverage for Team visits for patients who are unable to do so.

We also provide our patient with a copy of a brochure provided by the regarding “Health Resources for Your Child. Additionally, the Team Leader / SLP works with our patients’ public schools to help them qualify for needed services in their schools under PL94-142.