Statewide Craniofacial Anomaly Reporting and Referral Program

The Illinois Department of Public Health (IDPH), Division of Oral Health (DOH) administers the Statewide Craniofacial Anomaly Reporting and Referral Program (CAP). CAP was developed in 1986 as a response to many children born with craniofacial anomalies (CFA) who were not being treated by a CFA team in treatment facilities. In addition, children went without care from a CFA team until they were enrolled in the school system and their anomaly was then detected. Research has demonstrated the relationship between late-detected craniofacial anomalies and hearing loss.

CAP assists families of infants born with facial clefts through education and referral to a CFA team at specialized treatment centers. A CFA team of health care providers includes oral surgeons, pediatric dentists, orthodontists, dental hygienists, social workers, audiologists, speech therapists, pediatricians and other providers as needed. The program is a collaboration with the IDPH Genetics and Vital Statistics programs and the Illinois Department of Human Services.

CAP has three components:

- education for parents of infants with craniofacial anomalies;
- the development and distribution of educational materials for health professionals including hospital staff;
- educational programs at local health agencies, pediatrician offices and dental offices as well as for the “0-3 Programs” (a state grant program that links children to health care and social service systems).

Each month a DOH staff person receives birth certificate records for all children born with facial clefts from the Adverse Pregnancy Outcome Reporting System. CAP provides parents with information regarding the location of CFA team treatment sites for their child with craniofacial anomalies. The informational packet also includes oral health education on feeding techniques and oral hygiene for their infants special needs.

This information is mailed within the first months of life for most children with CFA. The materials for this program cost on an average approximately $1,000 per year and State general funds are used to cover the expense. The program annually reaches approximately one of every 800 families with newborns in the state.

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