

Identifying Sources of Disparities in Treatment of Children with Oral Clefts

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Oral clefts are among the most common birth defects in the United States. Cleft lip and cleft palate are correctable defects. Lack or poor-timing of treatment may lead to increased risks for the child including small stature size, speech disorders, emotional/behavioral problems, hearing loss, and dental problems. Whether disparities in timing of treatment exist is unknown. The primary goal of this pilot study is to identify sources of disparity in time to first cleft-related treatment among children born in Massachusetts with isolated oral clefts, with or without another minor defect, using new and enhanced disparity measures. A long-term goal of this study is to identify and address sources of disparities in the treatment of all children with craniofacial malformations, and subsequently of children with other birth defects.

Data for the study will be derived from the Pregnancy to Early Life Longitudinal (PELL) Data System, a public-private partnership between the Boston University School of Public Health (BUSPH), the Massachusetts Department of Public Health (MDPH) and the Centers for Disease Control (CDC). PELL is a unique population-based longitudinal reproductive health data system that includes birth and death certificate data linked to hospital discharge birth records and to the Massachusetts Birth Defects Monitoring Program data. The study population will consist of all 349 infants born in Massachusetts between 1/1/1998 and 12/31/2002 and diagnosed in the first year of life with an isolated oral cleft, with or without another minor defect.

New and enhanced measures of disparity will be developed, including race and Hispanic ethnicity, country of birth, educational attainment and age at birth and language preference, that take into account both parents' characteristics, as well as whether the father is named on the birth certificate. A more robust measure of health insurance will be developed through the use of two data sources available in PELL, the birth certificate and hospital discharge birth data. We will utilize two outcome measures: standard vs. late timing of treatment based on current medical practice, and median time to first treatment (both adjusted for clinical characteristics); and then we will identify the sources of disparity in timing to treatment based on our enhanced disparity measures. Multivariate biostatistical techniques will then estimate the association between our measures of disparity and the two time to treatment measures, in order to calculate relative risk by the various disparity measures and identify subgroups at increased risk for substandard timing of treatment.