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See, I've Grown: A Service Delivery Model for Young Adults With Cleft/Lip Palate

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ASHA 2016: Seminar 1-hour – After All, I’ve Grown Up: A Service Delivery Model for Young Adults with Cleft Lip/Palate

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Learner Outcomes: As a result of this activity, the participant will be able to:

1. Compare the various factors that have an impact on health related quality of life between children and adults with cleft lip/palate
2. Discuss the effect of cleft lip/palate on the adult’s functional communication skills and the impact of the cleft on overall quality of life
3. Describe the components of a model of care for the adult with cleft lip/palate and the role of the speech-language pathologist within this model

Summary

The young adult with cleft lip/palate (CL/P) is not merely a bigger version of the child with CL/P. This becomes increasingly clear as we continue to care for these young adults. One protocol does not fit all. The unique experiences and needs of the young adult with CL/P are very different than that of the young child. By the time the child reaches adulthood, he or she will have had the CL/P and alveolar cleft repaired, one or more sets of ventilation tubes inserted, endured years of orthodontia (Zajac & Vallino, 2017). Some may have had speech therapy and others may have had secondary surgery to improve velopharyngeal function for speech (Zajac & Vallino, 2017). In all likelihood, as a young adult, the person with CL/P will undergo orthognathic surgery, and with it may come changes in appearance and speech, which may lead to adjustment issues. However, treatment of young adults involves more than structural and functional alterations. At this age these young adults report concern about lip and nose appearance and dental/occlusal anomalies, problems that necessitate attention and further treatment (Bardach et al., 1992; Marcusson et al., 2002). They may also express concerns about school, employment, and relationships.

And yet, there is still another aspect of the cleft condition beyond that of structure and function. The presence of a cleft and the effect of treatment can have an impact on a person’s quality of life (QOL) (Huber et al., 2010). There are also factors beyond which a cleft can influence how a person will be affected (Havstam & Lohmander, 2011) – and this is different for every person. Over the past 15-20 years, there has been a paradigm shift in evaluating health care outcomes of young adults with CL/P (Zajac & Vallino, 2017) using QOL and health-related

quality of life (HRQOL) as outcome measures. The most widely recognized conceptual framework for describing the impact of a disorder is the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001). The ICF represents a shift from health condition and body impairment-centered descriptions of disability to a more comprehensive documentation, including a wider range of functionality indicators, such as activity, participation, personal and environmental factors. The emphasis here is on self-report rather than clinician report to gain a holistic perspective of function.

Lastly, for years, a child-centered multidisciplinary team addressed the needs of this person, and now the young adult must begin the transition into adult-centered care. In the United States, continuation with team care after 18 or 21 years is generally unavailable and the person must depend on community health care professionals for help. Community speech-language pathologists are generally not well equipped to treat such clients as courses in training programs tend to focus on the pediatric population with CL/P and scant attention is paid to the adult population in continued education.

In this session, we will describe the differences in needs and care between children and young adults with CL/P. Using an evidence-based approach we will discuss patient-reported experiences regarding the impact of the cleft and satisfaction with treatment. A service delivery model integrating QOL and HRQOL into the ICF framework will be presented. This holistic approach is well suited for the young adult with CL/P (Zajac & Vallino, 2017). These concepts will be defined and illustrated using examples of cases in which they were applied. Although there is no single assessment that can measure the complexity and multidimensionality of the young adult with CL/P, there are a variety of assessments and protocols that can be used to assess the different domains of the ICF, namely health and functional status, and clinical outcomes. These assessment measures will be described. Lastly, we will discuss transition of care and the barriers to care that reduce the QOL in the young adult with CL/P.

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