
Improving Feeding Safety and Speech Clarity for Clients with Moebius Syndrome

Sara Rosenfeld-Johnson, MS, CCC/SLP

Over the past 12 years I have evaluated or worked with over one hundred children diagnosed with Moebius Syndrome. In 90% of these cases, there has been improvement in the function of the affected oral musculature after oral-motor exercise intervention. The success rate is based on one critical piece of diagnostic information: are the affected muscles paralyzed or is there paresis?

Paralysis is defined as a complete loss of motor function, *including loss of sensation*. Paresis, on the other hand, is defined as partial paralysis affecting muscular motion *but not sensation*. In the case of paralysis, the goal of oral-motor therapy is to teach the surrounding muscles to compensate for the muscle that cannot move independently. With addressing paresis, the goal of oral-motor therapy is to improve the functioning of the affected muscles themselves.

Oral-motor therapy is a new area of intervention that is only beginning to gain the respect of the medical field. Prior to this type of therapy, clients with Moebius Syndrome were taught compensatory strategies to improve functioning in feeding and speech clarity. With the introduction of oral-motor therapy, however, our goals have changed dramatically. We now work toward the goal of "normal movement" in feeding and in speech clarity.

Once the diagnosis of paresis has been confirmed, direct work on improving mobility in the muscle can be initiated. This diagnosis is generally made by a physician. Prior to the medical diagnosis, however, an informal test can be given by the lay person if paresis is suspected. Place a non-flavored TOOTHETTE[®] that has been slightly dampened in a lollipop vibrator. Place the TOOTHETTE[®] on the inside surface of the upper lip beginning above the canine tooth. Depress the vibrator button as you gently move the TOOTHETTE[®] along the inside of the upper lip. Work across midline to the opposite side of the mouth, ending at the other canine. Immediately reverse the direction of the stimulation. Continue in this manner for one to two minutes, then remove the TOOTHETTE[®] and watch for any client response. The response may be at the muscle level in the form of minimal movement, or it may be a verbal statement that the client feels something. Since sensation is not present in a paralyzed muscle, any response to the TOOTHETTE[®] vibration will indicate that paresis, not paralysis, is present. This informal diagnostic technique can be used to evaluate the status of the tongue as well. Referral to the client's physician for medical confirmation should then be recommended.

A variety of oral-motor exercises have been used effectively with this population. The most successful are those that first address the awareness or "sensory" level of the muscle and then continue to work on movement in that muscle. For example, a series of increasingly difficult-to-blow toy horns has been used to improve the mobility and strength in the upper lip. The "Horn Hierarchy" works on improving abdominal muscle grading, velo-pharyngeal functioning, jaw, lip and tongue dissociation. There are fourteen horns in the hierarchy. Each one also addresses the development of specific speech sounds.

Improving upper lip mobility is a primary goal for clients with Moebius Syndrome. The inability to close or round the lips affects feeding safety as well as speech clarity. In the area of feeding, the lips are used to breast feed, drink from a bottle, drink from a cup, remove purees from a spoon, retract food back over the tongue to initiate a safe swallow, drink from a straw and control saliva (i.e., drooling). Without the ability to create a vacuum in the oral cavity, feeding can be "messy," and the client may also be placed at high risk for choking and/or gagging. In clients over the age of twelve months, the initial goal is generally lip closure. In addition to horns, a series of graduated lip closure exercisers has been used successfully. Once lip closure has been achieved, the "Straw Hierarchy" can be introduced. This sequence of eleven progressively more difficult straws is used to teach the coordination necessary for safe swallowing and to improve jaw stability, lip rounding and tongue retraction. Oral-motor/feeding therapy has been used effectively for improving lip closure and lip rounding as a means of improving feeding skill levels and feeding safety.

Instability in the muscles of the jaw has also been associated with many clients with the diagnosis of Moebius syndrome. Using a hierarchy of Graduated Bite Blocks has been noted to improve speech clarity on the conversational level and results in improved feeding safety. As the muscles of the jaw increase in strength and mobility the individual is better able to masticate food which translates into reduced risk of choking, gagging and food aspiration.

In the area of speech clarity, the lips are used for the following speech sounds: Consonants: Closed Lips: / m /, / b /, / p /. Rounded Lips: / sh /, / ch /, / j /. Lower Lip Tension: / f /, / v /, the vocalic / r /. Vowels: Rounded Lips: / oo / ("too"), / oo / ("good"), / aw /, Retracted Lips: / ee /, / ih /, / eh /. Diphthongs: / I /, / a / ("bake"), / o / ("no").

Many clients with Moebius Syndrome have intact or close to normal language systems. In other words, they are able to understand and to use vocabulary and sentence structure at their chronological age level. Unfortunately, many of these same clients cannot make themselves understood; their speech clarity is poor. Insufficient lip mobility is a major causative factor. Oral-motor/feeding therapy has been used effectively for improving lip closure and lip rounding as a means of improving speech clarity.

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