

Running Title: ORAL MOTOR DS

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The effect of oral motor treatment in Puerto Rican children with Down syndrome  
between the ages of 6 to 12 years.

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**SIGNATURE PAGE**

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The effect of oral motor treatment in Puerto Rican children with Down syndrome  
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**Table of Content****Chapter 1- Introduction**

I. Introduction	4
II. Problem Statement	5
III. Purpose of investigation	5
IV. Objective	5
V. Justification	6
VI. Definitions	6
VII. Information of the investigator	7

**Chapter 2- Literature Revision**

I. Introduction	8
II. Down syndrome	8
III. Symptoms	8
IV. Myths	9
V. Oral Motor	10
VI. Other Conditions	11
VIII. Treatment- Other	12
IX. Treatment- Rosenfeld	14
X. Conclusion	15

**Chapter 3- Methodology**

I. Introduction	16
II. Description of the population	16
a. Participant Selection	16

ORAL MOTOR DS	4
b. Inclusion Criteria	16
c. Exclusion Criteria	17
III. Research Setting	17
a. Procedure for the investigation	18
b. Informative Sheet	18
c. Participant confidentiality and data collection	18
d. Potential risks to research participants	19
e. Potential benefits for the participants	19
f. Potential benefits for the society	19
IV. Research Instruments	20
a. Data Analysis	20
<b>Chapter 4– Description of Participants</b>	
I. Participants	21-22
<b>Chapter 5- Discussion of Results</b>	
I. Questions	23-30
II. Conclusion	30
III. Recommendations	30-31
<b>References</b>	32

## Chapter 1

### Introduction

The National Association of Down Syndrome (2012) states that one in every 691 lives are born with Down syndrome. It is the most occurring chromosomal disorder and the leading cause of intellectual and developmental delay in the United States and in the world (Global Down Syndrome Foundation, 2011) is not related to any race, nationality, or religion. A person is diagnosed with Down syndrome when there is a cell division causing a person to have 47 chromosomes instead of the normal 46. Many of those born with Down syndrome need certain stimulus to provoke physical and intellectual development. There are 80% of women under the age of 35 who have Down syndrome infants. One of the common signs of children with Down's is poor oral motor defects.

There has been a great deal of investigation on Down Syndrome children with oral motor disorder yet there are not many studies done in Puerto Rico on 6 through 10 years of age on Down Syndrome children with oral motor disorder. Some have been given oral motor treatment (OMT) while others have not received treatment. In most cases, treatment begins when a child is in early intervention. Since Down syndrome children have facial structures such as lower mandible, lips parted, and the tongue assumes an anterior position over the lower teeth (Hennequin, 1999), the importance of oral motor treatment can reduce the features of drooling, clenching or grinding, and potential swallowing incoordination. The jaw, lips, and tongue are major movements necessary for the standard production of speech.

Sara Rosenfeld-Johnson founder of *Oral-Motor Therapy for Speech Clarity* (OMT) stated that children who do not receive intervention or therapy frequently demonstrates the characteristics of tongue protrusion, conductive hearing loss, chronic upper respiratory problems,

open mouth posture at rest, obligatory mouth breathing, and large tongue (Rosenfeld-Johnson, 2006). The *Oral-Motor Therapy for Speech Clarity* provides a tactile teaching technique which supplements traditional therapy (2001). The clients need the tactile component, which is used to improve muscle awareness, placement, and strength; the key elements in speech clarity.

### **Problem Statement**

The mouth is used to verbally communicate with others, to produce speech sounds, fluency, and intelligibility. Down syndrome is associated with impairments in spoken language (Kent, 2013). There are various investigation and research conducted on various aged Down syndrome children through early intervention to reduce oral motor problems, but treatment is not processed beyond preschool level. Consequently, there is currently not a sufficient amount of research conducted beyond preschool level or in Puerto Rico.

OMT strategies will increase oral mechanism, normal tactile sensitivity, improve oral movement structures, and speech sound productions to maximize intelligibility.

### **Purpose of Investigation**

The purpose of this study is to describe how effective was the oral-motor treatment in improving the overall speech intelligibility and swallowing skills in Puerto Rican Down syndrome children with oral-motor, speech and/or swallowing problems, between the ages of 6 through 10 years old, according to their parents.

### **Objective**

The objective of this investigation is to describe the parent's perspectives in how effective was the oral-motor treatment in improving the overall speech intelligibility and swallowing skills in Puerto Rican Down syndrome children between the ages of 6 through 10.

### **Justification**

In Puerto Rico there are not enough data on children receiving oral motor therapy beyond the age of preschool. The muscles with the structures of the face are important for the primary reason to communicate with others. This is one of the main reasons why oral motor treatment is necessary in elementary aged Down syndrome Puerto Rican children. The questionnaire will help determine how effective OMT is on children of various ages.

### **Definition**

#### **D**

Down syndrome

A genetic disorder, associated with the presence of an extra chromosome 21, characterized by mild to severe mental impairment, weak muscle tone, shorter stature, and a flattened facial profile (Dictionary, 2013).

#### **O**

Oral Motor

Relating to the muscles of the mouth and/or mouth movements (Medicinenet, 2011).

#### **S**

Stimulus

An agent, action, or condition that elicits or accelerates a physiological or psychological activity or response (Dictionary, 2013).

#### **T**

Traditional Therapy

Primarily auditory and visual components.

Tongue Thrust

The infantile pattern of the suckle-swallow movement in which the tongue is placed between the incisor teeth or between the alveolar ridges during the initial stage of swallowing (Dictionary, 2013).

### **Information of the Investigator**

Marelyn Diaz Centeno, who has 25 years of age, originally is from Millville, New Jersey. She graduated in 2009 with a Bachelor of Science in Speech-Language Pathology from The Richard Stockton College of New Jersey. She is currently enrolled in the masters Speech-Language Pathology program in the University of Turabo, in Gurabo, Puerto Rico. She has a family member who has Down syndrome and has not had treatment on oral motor therapy. At times, he grids his teeth and occasionally has signs of grueling. She is interested in this investigation, mainly because of the opportunity to help and educate those children with oral motor problems in Puerto Rico.



## Chapter 2

### Literature Revision

#### Introduction

One of the most common chromosomal conditions is Down syndrome. The National Down Syndrome Society [NDSS] (2012) states that there are more than 400, 000 people with Down syndrome, making 1 out of 691 births with Down's.

#### Down syndrome

Down syndrome is a chromosomal disorder in where instead of having 23 chromosomes; there is an extra or partial chromosome in chromosome # 21. Typically, this physical process occurs before birth. As a result of having this extra chromosome, the course of development is altered and causes various physical characteristics associated to Down's (NDSS, 2012).

Researchers have shown that women older then 35 years of age are more likely to have a child with Down's but recently statistics have shown that 80% of women under the age of 35 are having a child with Down syndrome. Researchers have yet to know the cause of why the extra chromosome. Down syndrome can come from either mother or father and does not depend on race or ethnicity. The risk of having another child with Down's is 1 in every 100 as stated in The NDSS (2012).

#### Symptoms

Children with Down syndrome can have various medical conditions. Most have common facial features such as flat face, small ears, slanted eyes, and a small mouth. The mandibular is protruded and low, the lips separated, and the tongue assumes an anterior position (Hennequin, 1999). They will also have a short neck, arms, and legs. Other factors are poor muscle tone and loose joints. There intelligence will vary. Down syndrome children can be at risk to have heart

defects, respiratory and hearing problems. Many of these conditions are treatable. Every child born with Down syndrome will have different conditions and each one will not be the same individual (NDSS, 2012).

### **Myths**

The NSSD (2012) illustrates various myths regarding Down's. The first one is that Down syndrome is a rare disorder. Down's is one of the most common genetic disorders. Second, the lifespan of a person with Down's is short. Recently studies have shown that the life expectancy has increased to the age of 60's. Third, it runs in the family. There is a small percentage that a family member who has a child with Down's will have another child the same. Fourth, children are born to older parents. Over the years there has been an increased amount of Down's born to younger parents. Fifth, their cognitive level is severe. Most children with Down's have a mild to moderate level. They are able to participate in private and public educational programs.

The Health Day News (2011) stated that researchers suggest that during the development of the fetus there is missing proteins in the brain. They have found that Down's have lower levels of specific proteins in the brain that can cause its symptoms.

Sara Rosenfeld Johnson illustrates in the article "The Oral-Motor Myths of Down Syndrome" that people commonly associate Down's with 7 visual features. The seven features are as follows; tongue protrusion, mild to moderate conductive hearing loss, chronic upper respiratory infections, mouth breathing, habitual open mouth posture, and the impression that the child's tongue is too big for its mouth (1997). There are myths that one thinks can not be prevented with therapies. She continues to describe that tongue protrusion is a learned behavior when bottle feeding an infant. When there is weak muscle tone, it reduces the effectiveness of the sphincter muscle in the Eustachian tube causing milk to enter the middle ear resulting in

chronic otitis media. Having multiple ear infections leads to mucous membranes of the respiratory system making it difficult to breathe from the nose, transferring to mouth breathing. When a child breathes through the mouth this encourages an open mouth posture. The open mouth leads the tongue to an anterior position because it is no longer maintained with a closed mouth.

Understanding the importance of oral motor at an early age can normalize the appearance of the oral motor system. Changing the position in how the child is feed can help the child reducing the changes of having tongue protrusion, chronic ear infections, and problems in the respiratory system and having the open mouth posture (1997).

### **Oral Motor**

Medicine net (2011) defines oral motor relating to the muscles of the mouth and or mouth movements. Down syndrome is commonly known as exhibiting poor oral motor skills. By having oral motor difficulties, it increases the affect of speech resonance qualities and restricts the range of motion for the articulators (Barnes, 2006). Down syndrome reduces lingual motility for speech production and some may have limited lip movement which is necessary for consonant and vowel production.

Oral motor control is a simple speaking task used to communicate. In Kent's article (2013), he describes commonly known technique called diadochokinesis to assess oral movement skills in a task that makes a maximum syllable repetition motion when dealing with the demands on language ability to reduce the speech rate. He also noted that Down syndrome children have reduced volumes of the airways, mandible, and smaller mid and lower face skeleton making it difficulty for one to control the movements need to produce speech, reduce drooling and grinding, and any possible swallowing incoordination.

Ruscello (2008) illustrates in the article that one of the sensory motor goals is to improve the accuracy of articulatory movements for a speech sound and incorporate those movements in speech. The nonspeech oral motor treatments increase strength, improve muscle tone, and develop muscle control essential for the population of Down syndrome. The exercises enable the motor skills for speech and motor memory of speech sound production. With a Down's facial features these oral motor exercises help increase strength and improve muscle tone, modify tongue, lip, and jaw positioning, and improve muscular control and function.

As a result from a survey, ASHA members stated that one of the interests was oral motor exercises. McCauley (2009) clearly states that when working to improve oral motor movements, it is important to consider what particular oral motor activity is appropriate when wanting to address the child's oral impairment.

An oral motor exercise is a beneficial way to address speech sound production problems. Many of the exercises used to strengthen the muscles for production of speech are: whistle blowing, side-to-side tongue wagging, cheek puffing, isolated tongue elevation, and pucker-smile alternations (Lof, 2008). Those exercises can increase the tone and strength of the speech musculature and provide opportunities for Down syndrome children to learn to use proper oral behaviors. Speech Language Pathologists (PHL) are more likely to have populations with Down syndrome when working with oral motor disorders.

### **Other Conditions**

Other oral motor disorder that can affect a child's ability to speak probably is Apraxia of speech (Nemours, 2010). Apraxia or dyspraxia is a condition that deals with the dysfunction of motor coordination and/or motor planning. It also affects an individual's ability to translate conscious speech plans into motor plans (Yudhasmara Foundation, 2012). Another condition is

the articulation disorder. This type of condition includes when a person lisps. They tend to leave out the consonants when speaking and substitute one sound for another (Yudhasmara Foundation, 2012).

Fragile X syndrome is another condition that is affected with the oral motor disorder. They are showed to have delays in communications skills. They are seen to have a phonological difficulty which includes consonant substitutions, omissions, and distortions. When in conversational speech, it is often unintelligible. With oral motor difficulties are reported to have difficulty with multisyllabic sequences, low muscle tone, motor planning problems, and tactile defensiveness (Roberts, 2003).

Genetics may also have a cause to oral motor disorder yet in some cases there is no evidence of what cause it. Most treatment plans are controlled with breathing techniques and relaxation methods to help strength the muscles used when speaking (Nemours, 2013).

Feeding and swallowing disorder as in children dysphagia also have oral motor deficits. The feeding disorder includes have issues when eating to suck, chew, or swallow. Swallowing disorder can occur during any of the following stages oral, pharyngeal, or esophageal. Some of the signs or symptoms are failure to accept different textures of food, difficulty chewing, excessive drooling, and difficulty breathing while eating. A feeding or oral motor programs is recommended to make the mouth muscles stronger, increase tongue movement, improve sucking, and coordinate the suck-swallow-breath pattern (ASHA, 2013).

### **Treatment-Other**

Beckman created the Beckman Oral Motor program in 1975 to better understand and help those with oral motor disorder. The BOM is used to improve movement to activate muscle contraction and to provide movement against resistance to build strength. The focus Beckman

uses to during the program is to increase functional response to pressure and movement, improve range, strength, variety, and control of movement for the lips, cheeks, jaw, and tongue. She also describes critical functions need for example during sleep to control secretions, swallowing, and maintain the alignment (Beckman, 2012). She states that oral motor skills are critical to basic function that occurs even when one is asleep, which controls secretions, swallowing, and maintaining alignment of the oral structures so that breathing is not interrupted. Having proper developmental of the oral motor skills enhance the progression from breast milk and/or formula, pureed foods, and table foods. This helps in the control needed for speech development, such as cooing sounds when infant, to articulation complex words needed during conversational speech. Having poor oral motor skills can result in delayed or reduced skill describe above.

Pam Marshalla produced the Marshalla Oral Sensorimotor Test (MOST, 2013) which is a comprehensive and quick assessment designed to put a numerical value on oral movement, oral tactile sensitivity, facial and oral tone, and respiration, phonation, and resonance skills. MOST works on those who have jaw, lip, and tongue movement problems, as well as children with feeding difficulties, neurological deficits, developmental disorder, and sensory processing disorder (Super Duper Publications, 2013). She is also the author of *Oral-Motor Techniques in Articulation & Phonological Therapy*. In this book, she states infant developmental stages, jaw facilitation activities, tactile sensitivity, lip retraction and how to get tongue/lateral margin elevation, how to stimulate /l/, /k/, /g/, /r/, and /s/ and how to reduce drooling and treat apraxia (Marshalla, 2012).

PROMPT is another approach when dealing with speech production disorders. This program focuses on integrating all domains and systems towards a better communication

outcome. PROMPT is used to assist in production, revise or change production, and/or integrate motor production with cognitive linguistic function (The Prompt Institute, 2011).

### **Treatment –Rosenfeld Johnson**

Since many Down syndrome children experience the following tongue protrusion, hearing loss, upper respiratory problems, open mouth when at rest, mouth breathing, and large tongue, Sara Rosenfeld Johnson created oral motor exercises than can help to clarify speech (Rosenfeld, 2007). An oral motor program can be incorporated using bite blocks, horns, straws, feeding techniques, and speech like exercises over various sessions. The jaw, lips, and tongue are essential elements when producing speech sounds (Rosenfeld, 2008).

Rosenfeld-Johnson indicates that the patients who are receiving the traditional therapy do not show improvement because they have a neuromuscular based disorder. The oral motor therapy will work if a tactile teaching technique which supplements traditional therapy is included (Rosenfeld, 2001). The tactile approach improves muscle awareness, placement and strength, all necessary for speech clarity.

One basic element when treating the Down syndrome population is the awareness that they have tactile hyposensitivity, an under reaction to tactile input. To achieve placement of the muscles, auditory, visual, and tactile stimuli is required. Auditory is given such as “close you lips”, visual is used for the client to see the instruction, and tactile can be used with a tongue depressor placing it between the lips. Repetition is needed to increase strength and muscle memory (Rosenfeld, 2001).

To begin treatment, exercises will focus on strengthening the jaw, lips, and tongue. Jaw exercises address strength, symmetry, alignment, stability, and grading. Lips exercises include close/open, protrusion/rounding retraction, lower lip retraction and lower lip protrusion for

speech sounds /m, b, p, f, v/. Tongue exercises require 50% retraction and 50% protrusion when suckle, 75% retraction and 25% protrusion when drinking from a cup, spoon feeding, and straw drinking, 75% stability when moving food from midline to back molars. Stability of the tongue tip when in elevation and depression are used to produce speech sounds such as /t, d, n, l, / and sounds like /k, g/ (Rosenfeld, 2001). Production of all speech sound in a co-articulated manner will depend on the stability of the back of the tongue.

### **Conclusion**

Many Down syndrome children are seen with the same appearance tongue protrusion, opened mouth, difficulty with the respiratory system and many others conditions. A child with Down syndrome should look and speak as normal to a child who does not have Downs. Through research, there is not enough data on children receiving continual oral motor therapy beyond the age of preschool. As Sara Rosenfeld Johnson stated, children with Down's should not have those noticeable facial features when given proper oral motor therapies. It is important that the muscles and the structures are working appropriately since it is the primary form of communication. This is a primary reason why oral motor treatment is necessary in elementary aged Down syndrome Puerto Rican children.



## **Chapter 3**

### **Methodology**

#### **Introduction**

The objective of this investigation is to describe how effective was the oral-motor treatment in improving the overall speech intelligibility and swallowing skills in Puerto Rican Down syndrome children between the ages of 6 through 12 according to their parents.

This will be a qualitative research which attempt to describe the parent's perceptions of how effective was the OMT in their children speech and language skills. In order to obtain this information, the principal investigator will interview parents of Puerto Rican children with Down syndrome that received OMT when their children were between the ages of 0-5. The interview will consist of open-ended and closed-ended questions.

#### **Description of the population**

##### **Participant selection**

The population that will be utilized in this study will be children in the age range of 6 to 12 years old with the diagnostic of Down syndrome who have oromotor, speech and language disorders. The purpose population will be selected by snowball effect. The snowball effect will be established through someone directly who has a child with Down syndrome, who will be referring me to other parents of child with Down syndrome. Patton (2002) describes the snowball effect as an approach for locating information-rich key informants; this allows the recommendation of different informants to accumulate new information need for the investigation. Criterion sampling is the review and study of all cases that meet some predetermined criterion of importance, a strategy common in quality assurance effort (Patton, 2002). The sample could vary between 3 to 7 parents with the characteristics described below. This investigation will take place in Puerto Rico.

**Inclusion criteria**

1. Parents of children with Down syndrome
2. The children must be between the ages of 6 to 12 years of age
3. The children have oromotor, speech, and swallowing disorders
4. The children received OMT between the ages of 0-5
5. The family lives in PR

**Exclusion criteria**

1. Parents of children without Down syndrome
2. The children younger than the age of 6 and older than 12 years of age
3. The children who do not have oromotor, speech, and swallowing disorders
4. The children who did not receive OMT between the ages of 0-5
5. The family who does not live in PR

**Research Setting**

The research will be conducted in PR. The interview will be conducted according to the parent location choice. The location should be a quiet, peaceful, without distracters, where only present the researcher and the participant.

**Procedure for the investigation**

IRB permission-There will be submitted to the IRB proposal of investigation with all the information required.

The researcher will be notifying through direct contact, via telephone, and email communication with the parents of the children with Down syndrome to arrange the interview. In this even parents will inform the researcher all possible participants according to the inclusion criteria in the research. Then, the investigator will give an informative sheet aimed at parents,

where they will be informing the parents what the investigation consists of and they will be invited to participate in this research study, in a free and voluntary manner.

Parents who agree to participate in this research study will be provided to them directly the informative sheet, which will include the purpose of the investigation, in which consists the participation, benefits, risks, and the opportunity to withdraw or refuse to continue participating in the process at any time they wish without any penalty. It will also include the information of the researcher (cell phone and email) so that the parents are able to communicate if they have any questions or need any other information of the investigation. Data collection will be collected through prior appointment, telephone interviews, and/or email communication. The interview will be audio recorded.

#### **Informative sheet**

The informative sheet is a document that explains the purpose of the investigation, in which consists the participation of parents, benefits and risks of the research, confidentiality of the participants and data, and the opportunity to withdraw or refuse to continue participating in the process at any time they wish without penalty. It also includes the contact information of the researcher (cell phone and email). Parents will have an opportunity to communicate with the researcher or the IRB of the SUAGM if they have any doubt or need any other information of the investigation.

#### **Participant confidentiality and data device**

To ensure confidentiality to the subject, the data will be decoded. There will be no type of indicator of the subject source. The documentation of the transliterations of the interviews will be stored in separate envelopes at the residence of the researcher in a drawer under lock and a period of five years as stipulated in the Compliance Office of SUAGM. The recording will be

deleted once the results of the transliterations have been documented. Once met with the five years, the documents will be shredded and discarded. This ensures that the participants have the protection of their privacy. There will not be mention of the identity of the participants, not the place where the inquiry took place.

### **Potential risks to research participants**

Some of the risks that may exist as an effort of this research can be misunderstood or misinterpreted questions or response choices. Allowing questionnaire through email can have a quite low return rate. Other risks that may exist are concerns, anxious, and/or nervousness. The risks are minimized by performing interviews outside of the lunch hour. Parents can also be emotionally affected before some situation before or in the interview. If any risks or concerns present and if necessary the participant can be referred to the Psychological Services Clinic at the University of Turabo.

### **Potential benefits for the participants**

The participants will have the opportunity to state their concerns, benefits, and performance of their child who had received oral motor treatment. They will also have their opinion on how OMT helped enhance intelligible of speech, if it helped better the quality of life when communicating with others, and their over all point of view on how effect OMT can be beneficial to increase speech intelligibility.

### **Potential benefits for the society**

Speech Language Pathologist will have a better understanding on the effectiveness OMT is on Down syndrome children. This will allow the views of parents concerning their child's treatment and speech intelligibility. Professionals and the community can have an understanding

about the feelings, experiences, and perceptions that the parents face in regards to their child's daily communication skills or problems.

### **Research instruments**

Patton (2002) defines a guided interview as a list of questions or issues that are to be explored in the course of an interview. This interview prepares to ensure that the same basic lines of inquiry are pursued with each person's interview. The "open-ended questions" are useful for probing respondents' feelings and opinions, without biases or limits imposed by the researcher. The "closed-ended questions" ask respondents to select an answer from among several choices that are provided by the researcher (Portney, 2009). It allows structured surveys that are self-administered using pen and paper or electronic function. Questionnaires are more efficient than interviews because respondents complete them on their own, data can be gathered from a large sample over a period of time, and they also provide anonymity, encourage honesty, and candid responses.

### **Data Analysis**

After the collection of data, there will be a transliteration of the same matter. Non-power connect systems will be categorized according to the topics on the different perspectives of the parents and the assertions in that match the same matter. The resulted will be analyzed by means of triangulation (investigator triangulation) already comparing the data obtained through research with data from previous investigations related to the prospects for parents with children of DS. After the triangulation will be a validation of the answers through interview by means of direct contact, telephone, and email.

## Chapter 4

### Description of Participants

In this chapter, the description of the participants who participated in the investigation are described. There was 7 participants selected who had to meet the following inclusion criteria.

The inclusion criteria were the following:

6. Parents of children with Down syndrome
7. The children must be between the ages of 6 to 12 years of age
8. The children have oromotor, speech, and swallowing disorders
9. The children received OMT between the ages of 0-5
10. The family lives in PR

The following presents the 7 participants and with the purpose of protecting their identity, they were assigned a pseudonym.

#### **Participant 1- Rosa**

Rosa is a married women who is 44 years old. Rosa and her husband adopted their daughter Rebecca. She stopped working and became a housewife to have better availability for her daughter. Rebecca is 8 year old attends a school in San Juan, PR were she receives one on one services.

#### **Participant 2- Maria**

Maria is a single mother in her early forties and works as a housewife. Her son Marcos is 7 years old and is a student in elementary school.

#### **Participant 3- Veronica**

Veronica is a married women and in her late forties. She is currently a stay at home mother. Victor is 7 years old and is in a self-contained classroom.

#### **Participant 4- Carmen**

Carmen is a 44 year old married women. She and her husband are currently employed. Carlos is a 9 year old boy and has no siblings. He is currently in a self-contained classroom. He communicates through sign language. On the weekend, he spends time with his paternal grandmother.

**Participant 5- Amanda**

Amanda is a 32 year old women who works. Her daughter Alani is 8 years old and has one sister. She is in a self-contained classroom in elementary school. Alani is very active and enjoys playing with her sister.

**Participant 6- Sarah**

Sarah is in her mid-forties and works as a housewife. Her daughter Sofia is 9 years old and is in regular classes. She has one sister age 11 years old.

**Participant 7- Marisol**

Marisol is a 43 year old and is currently employed a house wife. Her husband passed away 4 years ago. Her son Mathew is 9 years old and was recently transferred to regular classes with an assistant. He enjoys music.

## Chapter 5

### Discussion of Results

The purpose of the study is to describe how effective was the oral-motor treatment in improving the overall speech intelligibility and swallowing skills in Puerto Rican Down syndrome children with oral-motor, speech and/or swallowing problems, between the ages of 6 through 10 years old, according to their parents.

The resulted are analyzed by means of triangulation (investigator triangulation) already comparing the data obtained through research with data from previous investigations related to the prospects for parents with children of DS. After the triangulation will be a validation of the answers through interview by means of direct contact, telephone, and email.

The information was collected by 7 mothers.

**Questions 1-** ¿Cuál es la edad del niño o niña? (What is the age of your child?)

There was two girls in the age range 6-8 and one girl in the age range of 9-11. There was two boys aged 6-8 and two boys aged 9-11.

**Question 2-** ¿A qué edad comenzó a recibir terapia oromotora? (At what age did your child begin to receive oromotor therapy?)

There was two who started between the ages of 0-3 months. Two between the ages of 3-6 months. One between the ages of 3-3:11 years, one between the age of 4-4:11 years, and one at the age of 6.

Sara Rosenfeld Johnson states in her article "*Talk Tools Innovative Therapists International*" that it is important to begin oral motor treatment during infancy which starts at birth. The primary concern begins in nutrition. As Speech Language Pathologist, the job is to balance nutrition and have a successful way of feeding for children with Down syndrome.



According to the National Down Syndrome Society (2012), “the first years are most critical in the development of the child. Children who are born with Down syndrome typically face delays in different parts of development. Early Intervention is recommended, it can begin after birth. The sooner Early Intervention is started the better the prognosis”.

Even though the literature review states that oral motor treatment begins during infancy, it is noted from the parents that there are three children who begin oral motor treatment after the age of 3 years. As the “National Down Syndrome Society” has stated the earlier the treatment the better the prognosis. The prognosis and treatment will take longer for these children, especially since speech is one of the most important communication.

**Question 3-** ¿Recibió terapia a través del Programa de Intervención Temprana (Avanzando Juntos del Departamento de Salud)? (Did your child receive therapy through Early Intervention or the program Forward Together?)

Three parents answered yes and four parents answered no.

According the literature review, oral motor treatment begins at birth through the program of Early Intervention. As Speech Language Pathologist, the goal is to plan, prevent, and treat.

The NDSS (2012) mentions that the program of Early Intervention is a “systematic program of therapy, exercises and activities designed to address developmental delays that may be experienced by children with Down syndrome or other disabilities”. The Individuals with Disabilities Education Act requires the state to provide early intervention services for all those children who need to enhance their development and meet the needs of their children.

With the results from the parents, the program of Early Intervention was provided for three of the children yet four was given services through a different or private agency. Even with the IDEA act, early intervention was not provided.

**Question 4-** Mientras estuvo en el Programa de Intervención Temprana/Avanzando Juntos, ¿Quién le ofreció el servicio de terapia oromotora? (While your child was in Early Intervention/The program Forward Together, Who offered them the services of oromotor therapy?)

Four parents answered Speech Language Pathologist (SLP) and three parents answered a Speech Language Therapist (THL).

In the United States, a Speech Language Pathologist and a Speech Therapist are utilized and described as the same profession. There is a protocol in every state in regards to what the Speech Language Pathologist and Speech Language Therapist responsibilities are. As stated in the American Speech-Language Hearing Association, the Speech Language Pathologist is responsible to give oral motor treatment as soon as possible mainly through the program of early intervention.

According to the guidelines of Puerto Rico, the Speech Language Therapist is responsible to give treatment and the Speech Language Pathologist gives the evaluations and supervise. The results presented that even though the SLP are accountable to give evaluations and etc., four mothers stated that the SLP were the ones that provided the services and three THL.

**Question 5-** ¿Recibió su hijo terapia oromotora por otra agencia u organización? (Did your child receive oromotor therapy through another agency or organization?)

Six parents answered yes and one parent answered no.

As answered in question 3, services are given through the program of Early Intervention.

**Question 6-** ¿Cuál agencia u organización le proveyó el servicio de terapia oromotora? (What agency or organization provided the services of oromotor therapy?)

Three parent's received therapy through the corporation of the education department, three from the Down Syndrome Foundation, and one from private office.

Most services are provide through the program of Early Intervention from birth to prevent any long conditions through the department of education.

**Question 7-** ¿Cuántos años estuvo recibiendo terapia oromotora? (How many years did your child receive oromotor therapy?)

One child received oromotor therapy for 1-2 years, two in 3-4 years, and four more than 5 years.

According to the American Speech-Language Hearing Association (2014), it states that those who have “communication delay or disorder diagnosed, should start services as soon as possible”. Those who receive oral motor treatment at an early age, have a better prognosis and less years. How long treatment is given depend on what age the child began services.

The NDSS mentions that speech and language is a critical component of early intervention as well as other services. Down syndrome children may not speak until the age of 2 or 3, yet speech and language therapy has pre-speech and pre-language skills that are essential before saying the first words. Oral motor treatment skills are worked on such as learning to use the tongue, exploring objects with the mouth, and imitating or echoing sounds (2012).

The results showed that only one child with Downs received oral motor therapy less than a year while the others received therapy for more than 3 years. With Down syndrome children it is important to start oral motor therapy for the pre-speech and pre-language skills mentioned above.

**Question 8-** ¿Continúa recibiendo terapia oromotora? (Do they continue to receive oromotor therapy?)

Six children continue to receive oromotor therapy and one child does not.

**Question 9-** Marque las áreas en las cuales le trabajó el Terapeuta o Patólogo de Habla-Lenguaje. Indique si el funcionamiento es: (Indicate the areas where the therapist or Speech Language Pathologist worked with your child. Indicate what their function is:)

Three parents indicated all of the areas and their child was functional. Two parents indicated all of the areas and their child was normal. One parent indicated that the areas worked on were sensory, muscle tone, and salivation and their child was normal. One parent indicated all areas and working normal except intelligibility and is functional.

Áreas	Normal	Funcional	No Contesto
Sensorial	4	3	
Tono de los músculos	4	3	
Salivación	4	3	
Inteligibilidad	2	4	1
Tragado/alimentación	2	3	2

According to the literature review, Pam Marshalla (MOST, 2013) works on feeding difficulties, neurological deficits, developmental disorder, and sensory processing disorder. In her book, *Oral-Motor Techniques in Articulation & Phonological Therapy*, she works with infants on the developmental stages, jaw facilitation activities, tactile sensitivity, and lip retraction and how to get tongue/lateral margin elevation (Marshalla, 2012).

Sara Rosenfeld Johnson created oral motor exercises than can help to clarify speech (Rosenfeld, 2007). In this program, she works on using bite blocks, horns, straws, feeding techniques, and speech like exercises over various sessions. The jaw, lips, and tongue are essential elements when producing speech sounds (Rosenfeld, 2008). Rosenfeld (2001), also works on strengthening the jaw, lips, and tongue. Jaw exercises address strength, symmetry,

alignment, stability, and grading. Lips exercises include close/open, protrusion/rounding retraction, lower lip retraction and lower lip protrusion for speech sounds.

The results concluded that sensory, muscle tone, and salivation are the most areas of treatment worked on in Down syndrome children. Even though the literature review and the authors Marshalla and Rosenfeld work on various parts in the oral motor treatment.

**Question 10-** ¿Por qué cree usted que su hijo/a no progresó en las áreas de: (Why do you think your child did not progress in the areas?)

All parents have indicated that their child has progressed.

**Rosa**

“Mi hija está mejorando en todas las áreas”.

“My daughter is progressing in all areas”.

**Maria**

“Si, un montón. Él ha progresado”.

“Yes, a bunch. He has progressed”.

**Veroncia**

“Si, está progresando”.

“Yes, is progressing”.

**Carmen**

“Si”.

“Yes”.

**Amanda**

“Si, ella es bastante activa y muy selectiva. Está progresando”.

“Yes, she is very active and very selective. She is progressing”.

**Sarah**

“Si, está progresando pero todavía hay mucho en el camino para que ella este mejor”.

“Yes, she is progressing but there is still much in the way so that she can be better”.

**Marisol**

“Si, aunque todavía puede mejorar”.

“Yes, but he can still improve”.

**Question 11-** ¿Cree usted que el clínico estaba preparado para ofrecer la terapia? (Do you think the clinician was prepared to give therapy?)

Four parents answered with yes. Except three that answered the following:

**Sarah**

“No, porque la patóloga fue a un seminario de oromotor y no tenía la experiencia”.

“No, because the pathologist went to an oromotor seminar and doesn't have the experience”.

**Maria**

“Si, lo más importante es la comunicación con los padres”.

“Yes, the most important thing is communication with the parents”.

**Veronica**

“Si, está preparado pero necesita prepararse más en cuanto la terapia oromotor. El patólogo necesita prepararse mejor, le falta experiencia y necesita más conocimiento”.

Yes, he was prepared yet needs to prepare himself better when it comes to oromotor therapy. The pathologist needs to prepare himself better, there is lack of experience, and he needs more knowledge”.

**Question 12-** ¿Recomendaría usted al terapeuta, agencia, entidad, etc. que le ofreció servicio de terapia oromotora a su hijo? (Would you recommend the therapist, agency, entity, etc. who offered service of oral motor therapy to your child?)

Five parents answered yes and two answered no.

**Sarah**

“No, ya van 4 diferente patólogas que han trabajado con mi hija”.

“No, there has been 4 different pathologist who have worked with my daughter”.

**Maria**

“Si, a todo el mundo”.

“Yes, to all the world”.

**Question 13-** ¿Cuán satisfecho se siente usted con el servicio de Terapia de Oral Motor que recibió su hijo? (How satisfied are you with the services of oral motor therapy that your child received?)

Five parents answered “well satisfied”, “bien satisfecho”.

**Veronica**

“satisfecho”.

“satisfied”.

### **Sarah**

“decepcionado”.

“disappointed”.

### **Conclusion**

In this chapter, the conclusion are the results of the analysis of the information provided by the participants interviewed, taking into consideration the information in the literature review. Some parents feel that the pathologist is prepared to give oromotor therapy yet others get the impression that the pathologist lacks experience.

Three mothers indicated that their child began the oral motor therapy after the 3 years of age, affecting the speech intelligibility. The literature indicates that treatment should start before the first year of life, preferably after birth. None of the children received treatment with the program “Avanzando Junotos”. The children that began treatment before the age of 3 years received the services through a non profit foundation or through a private agency. Even though the parents manifested in general terms that they were satisfied with the services their child received, they considered that the clinician that offered the services did not have much experience with OMT. The parents believe in OMT, but they considered that one seminar is not enough to be an expert in OMT.

### **Recommendation**

The results obtained through the investigation with the conjunction of the literature review and the information of analysis obtained through the interview, the following recommendations are as followed:

- More SLP need to become certificated to give oral motor treatment.

- Investigate OMT outcomes with Puerto Rican Down Syndrome population.
- Treatment should begin after the infant is born and is diagnosed with Down syndrome.
- The children should be referred to “Avanzando Juntos”, right after being discharged from the hospital.
- Clinicians need to take various courses in OMT and should be supervised by another clinician with more knowledge and experience in this area.



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