

PONTIFÍCIA UNIVERSIDADE CATÓLICA
DO RIO DE JANEIRO



Pós-Graduação Lato Sensu em Língua Inglesa

ALINE CIDRINI ALVES

**AUTISM AND ENGLISH LANGUAGE LEARNING: A MOTHER'S
PERSPECTIVE**

Rio de Janeiro
2017



ALINE CIDRINI ALVES

**AUTISM AND ENGLISH LANGUAGE LEARNING: A MOTHER'S
PERSPECTIVE**

Monografia apresentada ao
programa de Pós-Graduação em
Letras da PUC-Rio como requisito
parcial para obtenção do título de
especialista em Língua Inglesa.

Orientadora
Prof^a Inés Kayon de Miller

Rio de Janeiro
2017

ACKNOWLEDGEMENTS

I would like to thank Professor Maria Isabel A. Cunha for the idea of working on my own children. Without her suggestion, none of this would have happened. Her immeasurable generosity and kindness when talking to me for the first time in the interview in 2012 when I said I was applying for PUC to have fun, and also the second time in 2016 when I told her that I needed something to run away from my problems. I did not know that this Língua Inglesa course would have such a great impact in my life. Something that was supposed to be fun became a unique experience for me and for my family as well.

I would also like to thank Professor Inés Miller for all her support throughout the course. Since the very first module when she trusted me and lent me a bag full of books about pronunciation until advising me during the research process. Her words and encouragement motivated me to believe that this paper had its validity. I will remember each smile and how comfortable was the way she looked at me in the most difficult days. Even when she did not know how I felt.

Finally, I thank my husband, Carlos Eduardo, for always being there for me.

Abstract

Alves, Aline Cidrini; Miller, Inés k. (Advisor). **Autism and English language learning: a mother's perspective**. Rio de Janeiro, 2017, 32 p. Monograph – Departamento de Letras, Pontifícia Universidade Católica do Rio de Janeiro.

While a lot of research can be found on the issues of second language learning in young learners, little has been said in terms of children with autism spectrum disorder (ASD) and the process of learning a second language. Some Studies in the past defended that autism occurred due to lack of parents' love. The aim of this paper is not only to describe my experience as a mother of twins with ASD, but also to analyze the quality of their English language learning development. In order to do so, I observed my own autistic children and their language development during seven months and how they reacted to my interference in their natural process. Inspired by the principles of Exploratory Practice (ALLWRIGHT, 2003) with a focus on understanding instead of problem-solving, I realized that each experience is unique. I created potentially exploitable pedagogic activities (PEPAs) in order to help me during my observation. Also motivated by the book *A queda* by Diogo Mainardi (2014), I managed to address my puzzles from a different perspective and hope that this paper can help other families understand their cases by enlightening them about how I investigated my family's process.

Key words: Autism Spectrum Disorder; children; English language learning development.

TABLE OF CONTENTS

Chapter 1

| | |
|-----------------------------|---|
| Introduction..... | 6 |
| Mother as ethnographer..... | 7 |

Chapter 2

| | |
|--|----|
| Literature Review..... | 11 |
| How autism was seen in the past..... | 12 |
| Autistic communication | 14 |
| Autistic in their own way..... | 15 |
| 2 nd Language Learning..... | 16 |

Chapter 3

| | |
|-------------------|----|
| Methodology..... | 18 |
| The children..... | 20 |
| The father..... | 21 |

Chapter 4

| | |
|-----------------------------|----|
| Data information..... | 22 |
| Exchanging Experiences..... | 24 |

Chapter 5

| | |
|------------------------------------|----|
| Understandings and discussion..... | 26 |
|------------------------------------|----|

| | |
|----------------|----|
| Reference..... | 35 |
|----------------|----|

| | |
|---------------|----|
| Appendix..... | 36 |
|---------------|----|

Chapter 1

Introduction

“Intelligence is what you use when you don’t know what to do, when neither innateness nor learning has prepared you for the particular situation.” (PIAGET, 1957)

I am a mother. I do not know what to do in many situations. I observe. I try to do my best. Piaget observed his children. I observe mine.

Autism is a multifunctional syndrome that affects not only the social development, but also the neural and biological aspects as well. (LORD et al. 2000 p. 355). Two scientists started studying autism in the 40’s – Dr. Leo Kanner, an Austrian psychiatrist who studied classic autism and Dr. Hans Asperger, also Austrian, who was a psychiatrist and a pediatrician. He focused on a less aggressive form of the syndrome.

Over the years, some hypotheses and therapies were proposed for the syndrome. One of them, by Dr. Bruno Bettelheim (1967), physiologist, stood up for parental lack of affect and the treatment consisted in the construction of a statue model of the autistic child’s mother so that the child could hit it in order to let the anger go away with punches and kicks. He was convinced that there was no organic foundation in ASD children. In some of his books, such as *Love Is Not Enough* (1950) and *The Empty Fortress* (1967), he described how difficult it was to work with autistic children since they were hated by their mothers. After that, it was proved that parents had no influence over the syndrome. Nowadays, therapies based on the children’s behavior are being developed.

Reading Dr. Bettelheim’s books made me think how studies evolved within the years. Having learnt about those mothers being made to feel guilty by scholars and society motivated me to go even deeper into the subject. Until today, obscure thoughts besiege families and their ASD children.

Research about the subject has increased during recent years. However, it does not cover the needs. In 1970, there was about one person with the syndrome in 2000 people. After 2005, the estimate number was already 1 person in 150 people (PERORAZIO, 2009, p 48). The latest study about this issue said that in 2014 one person in 68 had the problem (Revista Autismo, March, 2014). Even taking into consideration that many did not want to be exposed in the past, the number is still increasing very fast. Thus, we need to consider that more research would help the field to develop.

Having revised the literature above, I decided to do this research based on the observation of my twin boys who were diagnosed with Autism Spectrum Disorder at the age of 30 months. I am an English teacher and I have worked with children and adults. During my career I had the opportunity to work with some ASD students, however, I was not able to even suspect about my own children. They were forwarded to the specialist because their pediatrician signaled that they could be different from others. The doctors told me they were Autistic after nine months of exams and evaluations. They kept being observed and seven months later the medical team explained that we were dealing with a severe subtype called Classic autism.

Mother as ethnographer

Even with my previous experience, I did not have any idea about what to do to help them in their development. Later, English emerged naturally in our routine, since I usually bring a lot of work home. My sons showed interest in the colorful material from my work and started repeating some words when listening to some audios while I was preparing my classes or even teaching private lessons at home. Because of this, I believe I introduced some indirect “English lessons” to my twins and this is the aim of my paper. I need to understand why I chose to teach English in order to help my children improve their verbal development with Autistic Spectrum Disorder.

At this time, the book “A queda”, by Diogo Mainardi, served as an important tool to comprehend why my study would be relevant. Diogo in his book described what it is like to be a father of a disabled child. His daily experiences made me aware of simple aspects of our routine. His book had a great impact in the way I

have come to see my obstacles, through a positive perspective being also critical about treatments.

In this field, experiments are as important as research since each child is unique in responding to the stimuli in a particular way. Understanding made such a great difference in my life. Before knowing what was happening I was completely lost. I was not able to leave the chaotic world where I was. After getting the results of the exams and evaluations I realized that I had to observe more to become aware of what to do. Living in the dark is complicated, knowing they are ASD made me respect their development. Mothers have the idea they are able to control their children's lives. Mothers also want to protect their breed but first, it is essential to respect each person with their own characteristics and pace.

The inspiration for this monograph came from professor Maria Isabel A. Cunha, who told me that writing about my own sons was possible. Since the objective was to describe how my ASD children develop using a bilingual environment, I did my research most of the time at home or within familiar surroundings to foster a safe place for my sons. Even though the doctors advised me not to do it, I thought I did not have a choice. According to recent studies, no negative influence would take place if an autistic child were exposed to another language as it can be seen in Park's research (2014).

Research has shown that bilingual children tend to have stronger cognitive and linguistic abilities in such areas as concept formation and metalinguistic awareness than do their monolingual peers. Bialystock et al (2001) explains that bilingualism also serves a social function, as being bilingual connects people to specific communities. These connections build individuals' sense of identity. Maintaining bilingualism may therefore be important in order for children to feel like they belong to their heritage communities (Wei, 2000). Given the potential advantages associated with bilingualism, why do professionals advise parents to use only one language with their ASD children? Children with autism already struggle with developing social and emotional connections with others (APA, 2013). Is the recommendation to avoid fostering bilingualism truly in the best interest of the child? (SOYOUNG PARK 2014, p. 122)

As a Private English teacher I have many classes in my own house. For this reason, my twins were exposed to a second language since a very young age. First, because I needed to take care of them at the same time I was teaching at

home. Second, I believed that English could be something positive for them and finally teaching English is something that gives me pleasure.

In the development of this research, the notion of control and its relation with planning (ALLWRIGHT, 2003) was helpful. As a mother I wanted to have total control of my children's development as well as of their lives, which seems to be impossible. To solve my puzzle, it is crucial to work on understanding the situation. For this reason, I will explain how Exploratory Practice helped me, as I describe my experience and how it became a lead to my study in the following chapters. I believe that this research will not only help me as a mother but also I expect to be a better teacher, since the way I look at ASD children has changed.

In order to help me formulate the starting point of my work for understanding, I carried out an informal conversation with three different families with Autism Spectrum Disorder children, in order to gain another perspective of my problem. Aside from what the literature tells us about autism, it was essential for me to observe real life with real implications.

Being in touch with other children and families made me aware that there are many possibilities to treat the syndrome, since parents take into consideration their beliefs and preferences. Like other families, I chose what was close to me at the moment. I work with language, so this was very present in our daily lives and for this reason I introduced my twins to a second language. Some people are keen on food, so they choose a diet therapy; others are passionate about movement and sports, so the therapy is more active, and so on. There is no formula. Families only want to help their children to have an autonomous life.

To write this paper I also observed my children and made a diary with their progress during six months. Activities concerning language were also elaborated, some of them were planned and others just happened and will be used here due to their relevance. Since, in Brazil, the theory about the topic is still in development, interpersonal sharing has a great role in this exploratory research. This paper is about people trying to understand their puzzles and working to have a better quality of life, therefore, indirectly helping the autism community with their experiences.

In the next chapters, I will first review the literature. Then, I will describe the methodology used so that a meaningful analysis of the topic approached could be conducted. Finally, I make some final considerations and implications regarding the results reached and the conclusions arrived at by means of this research.

Chapter 2

Literature Review

According to Catherine Lord et al. (2000), autism, a neurodevelopmental syndrome, usually begins in infancy and the major concerns are deficits in social reciprocity and communication. In addition to that, repetitive behaviors, not calling their parents by name, specific hand and finger movements, not pointing or seeking out for others when happy are characteristics that can appear in preschool years. Due to its heterogeneous condition, children's development differs from one to another even between same profiles.

Since autism is possibly linked to genetics and neural development besides strong problems in social interaction, scientists search the neurobiological origins of social communication abilities and human behavior. At the same time spared skills and deficits in communication development can be seen. For instance, autistic adults may achieve successful employment, but rarely marry.

Autism Spectrum Disorder includes different types such as Childhood Disintegrative Disorder (CDD), Asperger, Rett, PDD-NOS, and autistic children. Although there have been many children with autism spectrum disorder with mental retardation and almost all have language delay, some cases differ from that, for example, Asperger's. Each ASD child needs to be seen individually, since development varies according to many aspects. The level of impairment, the stimulus and social interaction influence the communication learning process directly. For this reason, what may work with one child may not work with another.

In Table 1 below, we find different types of autism and functioning levels:

| Autism subtype | Mild ASD | Moderate ASD | Severe ASD |
|-----------------------------------|-----------------|---------------------|-------------------|
| Asperger's | Yes | No | No |
| Classic autism | Yes | Yes | Yes |
| PDD-NOS | Yes | Yes | No |
| Rett's syndrome | No | Yes | Yes |
| Childhood disintegrative disorder | No | Yes | Yes |

How autism was seen in the past

When I read about autism I repeatedly come across the word LOVE. Even in the most serious articles the word is there. It did not make any sense for me, as far as I am concerned, parents are supposed to love their children. Alongside with this word, I could see another very recurrent word in the literature: GUILT. I needed to understand what was behind all this, so I decided to check the history of autism and I was shocked. First came Kanner (1943, 1944), saying that autistic children did not relate to persons, though some of them related to objects. This suggested a lack of feelings in the ASD community.

In a not very distant past other theories proposed “refrigerator mothers” and lack of parental love as the source of the problem and as one of the explanations for autism. Bruno Bettelheim, who studied schizophrenia and autism very deeply in his psychiatric institution, came up with the theory that children were emotionally disturbed due to mother’s problems with their pregnancies and he also affirmed it was their fault.

Bettelheim wrote some books, but in the literature review I focused on two – *Love is not enough* (1950) and *The Empty Fortress* (1967). It is not difficult to infer the tone of the other books by the titles. Here are some others: “*Joey: A Mechanical Boy*”, *Scientific American*, (1959); *A Good Enough Parent: A book on Child-Rearing*, (1987). He wrote other books but these titles in my opinion but these made us, mothers of ASD children, feel at least curious.

Love is not enough was based on the observation of the emotionally disturbed children sent to the institute where he ran part of the research carried out there. The book starts saying what may be obvious for our generation: parents are so busy that we let our children too much time in front of the television and so on. Although the book is from the 50’s, it is our reality now.

Modern living conditions have made it much more difficult for parents to create a setting in for both their legitimate needs and the needs of their children. But more and more of them become weary of the struggle to arrange life sensibly for their children, while modern pressures create more and more insensible experiences which are added to the life of the child.

More and more they are exposed to crowded living quarters, to over-stimulating and incomprehensible experiences through radio and

television, and have to face almost daily some new gadget they must learn to master or avoid (BETTELHEIM 1950, page 13).

But as you read the book, the tone changes and it is possible to identify the author blaming the parents, or more specifically, the mothers.

The mother who indulges her child to show the neighbors how good a mother she is will often hurt the child as much as if she were only indifferent. The child will not understand that his mother may be acting on her own fears or anxieties. ("The ideal mother never gets irritated as I am so often"). He will sense only that he is being used, in one way or another, and indulgence received to impress others is no indulgence at all: actually, it is painful for him because he is misused for the mother's extraneous purpose. (BETTELHEIM 1950, p. 15)

Bettelheim built his book with examples of what mothers did wrongly and how they could trigger disturbance in their children. The author also said that he might sound a little bit harsh, claiming that his examples were meant to serve toward better understandings of the reactions of the normal child. He defended the idea that children were not born with disturbances, but that they were raised in an environment conducive to mental problems.

After reading this book, where LOVE is mentioned in the title, I could have an initial idea of how mothers of ASD children were seen in the past. Then I decided to read *The Empty Fortress* (1967), a book that, for me, was even more suggestive. I wished to see how his research was going on after some years and I was even more surprised. As a result of my reading, I understood the term Refrigerator mother. According to the author, Autistic children were not desired, for this reason they were not able of being loved. He divided his books in cases about autistic children. About one of the cases he wrote this:

Again I would like to digress, because the reason we began by ascribing Laurie's collapse to the ambivalence of the mothering persons seems of some theoretical importance. That is, so much is made in the literature of the attitudes of the mother as a causative factor in infantile autism.

Throughout this book I state my belief that the precipitating factor in infantile autism is the parent's wish that his child should not exist. While the same wish may not cause the same disturbance in other children, and while at some future time we may learn that some organic factor is a

precondition of autism, the fact is that almost all organic conditions that have so far been linked to this disease are also present in non-autistic children.

This seems to me reason enough to seek in parental attitudes for the reason why organic involvement – if such a factor should turn out to be typical – leads to autism (...) (BETTELHEIM 1967, p. 126).

In analyzing his books, I understood why we have such little literature about autism. One of the reasons is that the cause given in the past for autism was proved wrong. All research on this topic needed to start from scratch. Studies conducted until the 90's could not help in the way autism is seen today.

I have to confess that it took me some time to decide if this literature would be part of my research. My children were planned and loved since the beginning and I can see a lot of love in ASD mother's eyes when I talk to them. But we cannot deny history. Things change and we need to understand this in order to keep the ongoing process. Lessons from the past should help us in order to have a better future. Now I comprehend why many times I blamed myself. It is cultural. Mothers are usually blamed for many things, even when there is nothing to be blamed for.

Until nowadays, as parents, we can feel this influence in the ASD environment. Professionals tend to bring the importance of love in the conversations and try to get away with any guilt parents can bring with them. I reckon we are in the process, but a lot needs to be done in order to unsettle this cultural problem.

Autistic communication

The cognitive and the affective sides can have an impact in almost all human being communication levels, but concerning autism they can be even more decisive. Helen Tager-Flusberg, Rhea Paul, and Catherine Lord in their studies "Language and Communication in Autism" describe how ASD individuals achieve (or not) their communication. It has been said that the symptoms of ASD children are extremely variable, which reflects different language development. Tager-Flusberg and Joseph (2003) proposed two language phenotypes among verbal ASD children: children with normal linguistic abilities (phonological skills,

vocabulary, syntax, and morphology) and children with autism and impaired language skills that is same as the phenotype found in specific language impairment.

In this paper I will focus on speaking children with autism, however, it is relevant to mention that very few researches with non-speaking autistic children have been done “due to a dearth of communication on these children without functional language, the causes of failure to acquire speech are primarily speculation” (TAGER-FLUSBERG, 2003, p. 336). Subgroups are also proposed to identify some particularities in both cases of autism.

Parents notice difference in ASD children development when the children are about two years old. However, because the syndrome can be variable, it is possible to suspect earlier or later. Usually ASD children start saying their first words, very often with difficult intelligibility similar to other children but later there is a “language regression”. Although language is present, communication and interaction are difficult to be reached. ASD children are most likely to repeat what was said when they do not know how to act or answer, which is called echolalia. There is also a lexical matter and some difficulty in understanding metaphorical language. In addition, difficulty using pronouns is viewed as part of a more general difficulty with deixis, the area of language that codes shifting reference between the speaker and the listener.

Conversational contexts are more challenging to ASD individuals since more than language is involved. Interaction relies on semantic and pragmatic social adaptations. Although more challenging, it is possible since another strong characteristic of autism is the ability of changing. ASD people overcome their language problems and adapt what they are capable of doing to what they need to do.

Autistic in their own way

Despite the insufficient research studies in the field in Brazil, Calazans and Matins (2007) provide important information that helps us to understand the situation a little bit better. They explain the differences between autism and cognitive deficits. They argue that autistic children value words very highly, and for this reason, they answer and communicate in their own way, but this does not

mean they are not able to comprehend things. They focus on the clinical aspect of the disorder from a psychological perspective, reporting the behavior inherent to ASD people.

The psychological view concerning the treatment of autism is complex, however, a lot can be inferred from analyzing therapists' studies. First, autistic people choose to be alone in their own world avoiding direct communication. Furthermore, according to Calazans, those who are considered normal tend to try to forget the autistic nearby. This is probably so, because ASD people might cause discomfort and anguish.

To be honest, I agree with this view. It can be difficult to be together with autistic people. It may be challenging to face interaction. On the other hand, the studies discuss about patients and how to deal with them. Since I am a mother, I do not dare feel uncomfortable. I take into consideration what has been said and adapt it to my reality. Calazans' article finished with a question about how possible it is to decrease the clinical intervention to a census of the symptoms and control of the subject (my own translation). In my study I will discuss the notion of controlling and whether it can be considered positive or not.

2ndLanguage Learning

Bearing in mind what was said above when I discussed ASD diagnosis, one immediate question that comes to mind is language development. Soyoung Park (2014) in his article, Bilingualism and Children with Autism Spectrum Disorders: Issues, Research, and Implications, argues in favor of the benefits concerning bilingualism and ASD children. Due to the possible problematic communication that characterizes the syndrome, clinicians and educators had been advised to wisely avoid bilingual environments by (BIRD et al, 2012; KREMER-SADLIK, 2005; WHARTON, LEVINE, MILLER, BRESLAU, & GREENSPAN, 2000; YU, 2009). However, research had pointed out that bilingual children are more likely to have positive development in cognitive and linguistics abilities (Bialystock, 2001; PETERSEN, MARINOVA-TODD, & MIRENDA, 2012; WEI, 2000). With the

advantages of bilingualism, the advice of professionals to raise ASD children without learning a second language has become questionable.

Recent research in the field has shown that, in fact, there is no significant difference between monolingual ASD children and their bilingual peers. Moreover, a few language advantages may be seen with children who are exposed to a second language. Therefore, ASD children are able to learn a second language without suffering negative interference in their development. Although some research has been carried out in the area, it is still unexpressive if compared with the increasing demand. The expansion of the literature on this issue would help parents in their path with their children.

Chapter 3

Methodology

As mentioned earlier, very little is known about Brazilian ASD children and their development. Probably for this reason, many doctors tried to discourage the use of a second language with ASD children. Finding specialized professionals is a challenge, mainly in Rio de Janeiro. There has been an increasing concern about autism even knowing that the number of autistic children cases is growing and yet very little information about it is brought to light. Campaigns about Autism Spectrum Disorder are not common in Brazil. We have April 2nd as the World Autism Awareness Day, but it is not an important date in our Brazilian calendar. The lack of information can be seen in different areas, for instance, colleges preparing teachers should have the subject concerning inclusive education since 1996, according to The Brazilian Ministry of Education (MEC).

Furthermore, since September 2001, Article 18 of Resolution e No.2 establishes the National Guidelines for Special Education in Basic Education.

It is the responsibility of the educational systems to establish norms for the operation of their schools, so that they have sufficient conditions to elaborate their pedagogical project and can count on qualified and specialized teachers, as foreseen in Article 59 of LDBEN and Based on the National Curricular Guidelines for the Education of Teachers of Early Childhood and Early Years of Elementary School, at the intermediate level, in the Normal modality, and in the National Curricular Guidelines for the Education of Basic Education Teachers, at a higher level, Teachers Education Course.

Despite the social importance of having well prepared teachers, it does not mean that our universities are offering enough information or support to help prepare professional educators. I asked some professionals that work with me in the public school system about their knowledge about the topic in order to know if they had studied the subject during their undergraduate studies. I also talked to professionals in the private school system and people who are still studying. The result shocked me since ASD children can be found everywhere in an increasing

number. To make matters worse, Autism Spectrum Syndrome is barely mentioned during the academic years as can be checked in the table.

| Teachers and areas | Studied about autism superficially | Studied about autism (or other impairment) deeply | Did not study about autism |
|---|------------------------------------|---|----------------------------|
| Teacher 1 – Geography Conclusion in 1994 | | | x |
| Teacher 2– History Conclusion in 1995 | | | x |
| Teacher 3 – Pedagogy Conclusion in 2001 | | | x |
| Teacher 4 - “Curso Normal” Conclusion in 2003 | | | x |
| Teacher 5 – Physics Conclusion in 2007 | | | x |
| Teacher 6 – Pedagogy Conclusion in 2008 | x | | |
| Teacher 7 – Pedagogy Conclusion in 2008 | | | x |
| Teacher 8 – Physical Educat Conclusion in 2008 | | | x |
| Teacher 9 – Languages Conclusion in 2009 | | | x |
| Teacher 10 – Pedagogy Conclusion in 2013 | x | | |
| Teacher 11– Pedagogy Conclusion in 2016 | | | X |
| Teacher 12 – Languages Conclusion in July 2017 | | | X |

Table 2 - Content area teachers and their studies about Autism.

In addition to the information deficit revealed in Table 2 above, famous people who could be used as reference for productive lives are unknown by society. Among many others, Einstein and Isaac Newton were Autistic (Royal Society of Medicine, England 2014) and recently Leonel Messi was diagnosed with Asperger, which belongs to the Autism Spectrum Disorder (MACÍAS LÓPEZ et al. 2014).

The children

The children are three years twin boys, who have been diagnosed with Autism Spectrum Disorder at the age of 33 months. Due to the fact that they were too young, it was not possible to determine the level at that point, but I supposed it was not a severe level, since they were able to speak (even though this speaking does not lead to communication) and have social tolerance. To my surprise the doctors decided to test their level and they classified both at the severe level. One is with 44,5 on a scale of 50 and the other is 39. Although as a mother I do not agree with the result, I know that in two years or more they will have a new evaluation to redefine the level of the syndrome, so I have to wait and observe to see how things are going to be in the future.

When they were 12 months old, the pediatrician suggested that the twins were different if compared to other children that he was familiar with. In spite of that, it took me one year to look for help and after nine months under investigations and exams at the “Rede Sarah de Reabilitação”, a federal medical institution in Rio de Janeiro, the diagnosis was confirmed.

In order to monitor the situation, in this study, I firstly used observation. During six months, I observed the twins’ reaction when exposed to the English environment. I observed if they showed interest in repeating new sounds or not, besides the association with the functions of the words or the relation to objects. Another important aspect was if they wanted to use Portuguese. I recorded some moments in order to analyze them later and I also took notes about their development. If they were exposed to a specific vocabulary for the first time I observed if they were able to reproduce it or not.

The second method used was Potentially Exploitable Pedagogic Activities (PEPAs). Three same activities were prepared in English and Portuguese taking into consideration their reactions or preferences. The purpose of these PEPAs was to consider if they really were having positive outcomes in the English sessions and check if they were acquiring both languages without negative interference in their development. The activities will be described later on in the text

The father

I also talked to the children's father about the topic. Since the whole process involves understanding, it took me a lot of time to be brave enough to approach him and for me to understand that I was afraid of hearing something I would not like to. Although we have been in a relationship for more than ten years, being a mother of ASD children scared me and maybe for this reason I put myself in a lonely position. I was hiding from others' opinions and comments. This is another important influence of this research on my life, because I believe that if it had not been due to this paper I would not have talked to him about this issue at all. We create obstacles that we do not even realize and only with people's help we can understand things better.

Chapter 4

Data generation

Songs were suggested by psychologists. According to professionals, songs are able to help autistic children to organize their thoughts, collaborate with their problematic pronunciation of specific phonemes and help them to make meaning of abstract things. Songs are also predictable once you know them, so this makes them confident. They know what to expect. Another benefit I could observe concerning the use of songs with my children was that it helped them to organize their routines. There was a song to brush their teeth, another song to take a shower and so on. We are used to doing this at schools with our students, but we rarely take this experience home. There were also songs to avoid fights and to organize the toys.

I chose songs that they were singing at school as well. In addition to this, the songs help us to break the ice and recover their attention when necessary. The rhythm and movements related to the songs call their attention and they also perform what the song is saying. For instance every single time I sing the song about going to the potty, they pretend or sometimes they really go to the potty.

Potentially Exploitable Pedagogic Activity 1– Songs

Sing and mime: some songs were collected in both languages in order to grasp if they had preferences concerning language as well as they were able to comprehend the meaning through miming the songs or making the corresponding sounds. This was the objective, but something different happened. The first song, “Itsy bitsy spider” (Appendix I), was a turning point in my life. They were not able to speak and the few words they say I could not understand. Once, leaving the Zoo they saw a spider and started to sing in Portuguese the whole song. It was the first time something like this happened. I could understand the song and the most important thing for me, was that it was in a context. Due to the communication barrier, songs became an option to start this process.

Because they sang Itsy bitsy spider spontaneously, now and then when I realize they are too quiet or in their own world I make a spider with my hands in order to have them singing for me. This is a way I found out to make them leave their isolation and interact. Any interaction is better than none.

The “Alphabet Song” (Appendix II) also played an important role in our lives. I live a paradox because on some occasions they do not concentrate while in others moments they get involved with an activity and nothing else matters. I noticed that putting the letters in alphabetical order called their attention; moreover they seemed to like having their favorite cartoon characters singing this song. It is simple to find this song in different versions on the internet, so it was very useful when I needed to switch the topic or have them concentrate a little bit in order to calm down. I usually let crayons in their bathroom with the alphabet written on the walls while they are having showers, so they can color the letters while listening to the song. Some ASD children have this need to order things; since my boys like letters, this makes them feel safe.

Here the letters of the alphabet are sung in a musical rhythm with their favorite characters from TV shows, such as Thomas and friends.

Another song which, I may say, was a landmark in our lives is “Old McDonald” (Appendix III). Children usually imitate animal’s sounds but mine were different. I did not have even the perception if they identified the animals before singing this song. Practicing this song with them helped me teach them about animals. We also bought toys and books for this theme to be more real for them. After some months of practice we went to a farm and they made meaning of what was happening. It was moving.

Songs with numbers were also used; however, they only performed them in English. It took them a while to say the numbers in Portuguese.

Potentially Exploitable Pedagogic Activity Two – Daily life vocabulary

Every month I put on their bedroom walls flash cards with new pictures that represent the new words I expect them to learn. I introduce the vocabulary in English and the family teaches them the same concepts in Portuguese. I am aware that it is an ongoing process and they will probably need this intervention for

more time until they have the minimum vocabulary to be autonomous in their lives. In order to make it more fun, posters with their favorite cartoon characters are hung on the wall as well. The characters help them to formulate simple sentences such as “Thomas is blue and Percy is green.”

Potentially Exploitable Pedagogic Activity Three – Pre-school vocabulary

They learned colors, shapes, numbers, alphabet, animals, food, etc. at school in Portuguese, so I prepared many posters with their help on different days to see which language they preferred. The posters were collaborative and I tried to respect and follow the language they chose to use during the preparation.

The other method I used was a diary, where I kept notes regarding spontaneity, place, frequency and context of language. It was also relevant to identify if the language led to meaningful communication or whether the words were said for the sake of being said without a purpose or with a request.

Exchanging experiences

I also had informal conversations with people who live with ASD children, such as mothers and fathers, teachers, aunts and uncles. Among other aspects relevant to this paper, I focused on what each family was doing to help their children’s development. The conversations were not guided and happened naturally and in some cases, even by chance. One of these encounters happened at a child’s birthday party, when a father approached me because he recognized the problem with my boys and he wanted to talk since both of his children are also autistic. The conversation lasted one hour and I could observe his children for three hours.

Other two conversations happened because I teach at home and some of my private students observed that something was different with my boys. These students started to share their own experiences with me. We had two moments to talk about the issue and how the family worked on the problem.

A conversation with a teacher of one specific student was planned and the observation of this child lasted six months. We had two moments to talk about him: one at the beginning of the research and another at the end of it.

The purpose of having other children included in this research is to understand what has been done in Brazilian families, such as therapies and treatments. Sharing ideas and experiences is a valuable tool for ASD children. No child is similar to the other, so the variety of sources is a key to achieve positive outcomes.

Chapter 5

Understandings and discussion

When I began this exploratory research it was evident that I would not arrive at clear results since the research topic is very broad and the methodology absolutely open. For this reason, I concentrated on observing the twins' development as well as trying to understand what was happening in our lives. The process itself was enlightening; I could not only see how they developed in their language learning process but also what else they needed. Language plays an important role in our society, however, communication goes beyond. One can coach a child to speak but, in the case of autistic children, it is much more challenging for them to internalize the social context. During the activities and the period of observation it was possible to follow how the twins gained vocabulary. They became able to sing full songs as well as greet people. Relatives got satisfied because they called their names. Despite accomplishing many goals, their verbal evolution was not progressing as I hoped. The interaction did not happen the way I had expected.

Knowing how to speak a lot of words may have not worked well, as they do not understand what to say and when to say things. A lot of words being repeated infinite times out of context interfere in the communication process. It really does not matter if they choose Portuguese or English at the moment of speaking, once it is very difficult to make meaning out of their discourse. Some aspects that can be clearly observed are echolalia (a common stereotype in the ASD community that consists of repetitive speech), they use the language and vocabulary of their favorite cartoons all day long (even to do their daily activities such as brush their teeth or eat) but they do not follow instructions or commands and scream when they are not able to convey their ideas or necessities.

Even though the twins had been exposed to the same process, their development was slightly different. João seemed to have better outcomes since he is able to convey simple ideas, even using language in a rudimentary way and with the entire echolalia influence. José, on the contrary, does not make meaning of

words and utters things for the sake of uttering them. It is not possible to communicate with him in a direct conversation for instance.

Having said this, one aspect in this study has begun to clarify my perspective of the ASD world. It is a fact that the twins had their obstacles due to the syndrome, but it may be taken into consideration that being exposed to English and Portuguese did not have a negative outcome for them. Truly, being bilingual probably helped them to practice different phonemes and also to memorize a great number of words, abstracting the meanings and switching from language to language.

As mentioned by researchers Kremer-Sadlik (2005), bilingual families of children with ASD are often advised by child development specialists to choose only one language. According to these studies, the recommendation stems from the belief that bilingualism would have a negative impact on language development in children who already experience significant challenges in this area because they have ASD (HAMBLY & FOMBONNE, 2009). In Brazil, professionals follow this idea, but while observing my own children, I could not see any negative impact in their development. To make matters more complex, comparing my boys with other ASD children, they seem to have accomplished more words than ASD children not exposed to a second language. Although it is relevant to admit difficulties in interaction due to the syndrome, they do not seem to have been affected negatively by a second language.

Observing, or monitoring in Exploratory Practice terms, was the most difficult activity because one wants to see what one expects and most of the times this is not possible. It was necessary to focus on what I was seeing instead of what I desired to see. During the six months some aspects called my attention more than others. Firstly, there was a difference between the twins' development. Even though both were exposed to the same activities and stimuli, they performed in totally different ways.

João internalized the vocabulary faster and was capable of making meaning of what he was saying, as mentioned earlier. He is also able to make simple sentences with content words such as "João sad" and *João casa bisa* (*João bisa's house*.) It seems that for him it does not make any difference if he uses Portuguese or English. He does not use pronouns or auxiliaries, but it is possible

to communicate. The negative aspect in his development is that he prefers to hide instead of trying to speak whenever something bothers him. If he gets hurt he does not say or make any noise, for this reason it is necessary to be very careful. Once he got really hurt and when we found out medical intervention was needed.

José lives in his own world. He says a lot of words all the time, but many of them are from cartoons. He says the names of his favorite characters; he sings a lot and counts. He only copies the sentences from other people and does not use pronouns or auxiliaries either. He also does not complain when something is wrong or when he gets hurt. Before knowing that he is autistic I did not use to pay attention to their small signals. There was an experience that made me suspicious, I closed the car's door at his hands but he did not complain or cry. I only saw about ten minutes later. Thanks God nothing serious happened, but this may exemplify how some ASD children can be tricky concerning pain. Because he escapes from reality, he is able to socialize more with strangers. In fact, he does not interact, but stays next to them repeating the words he wants. It seems that people do not represent much for him.

Regarding the main objective of this paper, which is a case study in order to understand the potential influence of exposing ASD children to a second language, it is possible to say, for the participants focused, that being able to speak two languages does not seem to delay the learning process. Despite facing many difficulties, it is not possible to say either that the second language had a negative impact on them or that it represented a great advantage. Being exposed to a second language helped them practice more words and phonemes; however, it did not seem to make a difference in the communication process. Sometimes they use both languages at the same time, for instance two *carros* (two cars) can be heard when they are playing. Comparing to what is being said in the literature about non-autistic children, it would appear that the learning process is similar to other children processes.

By exploring the PEPA I could observe different aspects. The activities with songs enabled me to realize that the twins have a great memory. They are able to pick up a song very fast, and more than that, spontaneously, when exposed to both versions – Portuguese and English, they chose to perform in English with a

specific group, for example their classmates, and in the other language with their relatives that do not know how to speak both languages.

Concerning the activity with numbers, whenever they were asked for numbers in Portuguese they recognized them, but they preferred to utter them in English. I know that they are able to reproduce the numbers in Portuguese due to their school activities with their regular teacher. Numbers play a great role in their development, since the topic is their favorite activity. They love counting, playing and singing everything related to numbers.

The second activity, by which I tried to broaden their limited set of words, involved daily vocabulary. During the period of 6 months, from 30 months old until 36 months old, I recorded monthly some words used in our daily life and had them listen to them once in a while. Along with the recordings, I also stuck on the walls pictures representing the words in order to make them understand the meaning of the new vocabulary. In this list I included relatives, people from our acquaintances, commands and requests, for instance, picture words such as “I need water”, “It hurts”, etc. This activity was the most successful one because even when they were doing other things in their bedroom, they could visualize the pictures and still make connections.

Every single picture representing a word that went to the wall was spoken in an understandable way by the twins after the activity, even though the words were said out of context. For instance, “Good night”, even being daytime; other expressions were not being used to communicate their meanings – the most important thing is that the words were being said. For me, this was a really great improvement. I understood that speaking is one of the biggest challenges an autistic person can have. So, saying something in this case is better than saying nothing.

The pre-school vocabulary activity has helped them at school. Their teacher during the school year talked to me about the delay she could see in their learning process. They were in a different process of speech development. Yet, after reinforcing what they have learned at home, they were able to improve at school. I reproduced everything they were learning in their pedagogic environment at home in a playful way. I used to produce the posters with their help, so they had fun

making them. While we were working on the topics, we also had great moments of enjoyment.

Despite using English to elaborate the posters, whenever they prefer to speak Portuguese I switch my language to adapt to the activity. At the end of the work they always try to present their work, to people that come to visit them. If the person knows English, they use English, but for instance with their great-grandmother they try to use Portuguese most of the time. I believe she is the most reluctant user at home. As far as I can see, she forces Portuguese with them. So they already know she is not going to answer them and for this reason they try to communicate in Portuguese.

The frequency of new topics varies according to their school program. Short themes tended to last one week, so I elaborated one poster per week. Other complex themes lasted a little bit more, so I divided the topic and elaborated more posters. What is relevant to mention is that each poster was displayed for at least one month so that they could internalize what was going on. They probably were able to visualize their progressive learning process. It seemed that they were proud of their development.

In the diary I wrote everything that seemed to be relevant to this paper. I started with the conversations I had along this period. It was surprising to find out about the number of ASD children in our environment. In one of the attempts to find a new school for them I had to face this difficult reality. I was trying a public school and in one of the schools there were three ASD children, so they could not accept two more. According to our local laws, the public school should reduce the number of students to receive the special needs ones. For each special student the group has to have five students less. The principal told me that, for the first time, she was not able to serve the community. For each special child that the school accepts, she has to decrease the number of students, in order to be able to offer quality service and also they need a helper for each. There were not enough specialized professionals for everybody. In a school of 100 children, three were autistic and two had Cerebral palsy, not to mention the ones with problems but without medical support, which has been a serious problem for schools.

In a conversation I had with a second grade teacher of an autistic child in a different public school, she described his development along the period they lived together. This child started school with the age of four. He did not speak or interact. But through the years his development was striking. He started to speak, play with other children and even to read and write. The most difficult part, according to the teacher, was to deal with feelings like jealousy and frustration. His family cannot afford all the individual therapies he needs, so he is also in a public program for ASD children and he is responding very well to the treatment. When asked about his favorite school subjects she said he likes English and maths. He has a person who helps him in his pedagogical activities.

During this research paper, I also talked to a father of two autistic children. They are not twins, the girl is 12 years old and the boy is 3 years old. She has a mild level of the syndrome, being able to have a pretty normal life. However, there is something relevant to mention regarding this case. She speaks English fluently since she was 3 years old. She seems to like the subject a lot. For this reason, she started studying in an English course since a very young age. On the other hand, she has many problems at school with maths. She prefers languages to numbers.

The boy has a moderate level of autism and has been through different treatments and attended different schools. His father confessed in our conversation that his life is so tiresome, not to mention, expensive. The family schedule is always busy whereas the results are reached at a slow pace. While I focused on the language to help my children, this father focused on the movements and commands. He hired a famous consultant from another state to help him. They created a specially prepared room with different tools to help the boy develop. The father also paid courses for the boy's teachers expecting that all their investment would have a fast outcome. Having that been done for a year, he realized that it might have been a better idea to respect his son's space and nowadays he tries to control his anxiety. He also decreased the number of professionals helping him. Recently, he has been pursuing balance instead of speed.

While doing this research I noticed an emerging pattern – if one sibling is autistic, the other is much more likely to have the same problem. In my case, my children are twins and autistic. But I talked with three other families, and

understood that even though the children are not twins, they are still both autistic. One case is that of the family which I mentioned in the previous paragraph. Another family lives in the USA and I got to know them through a student of mine. The children are her nephews. She told me that they are boys and both have ASD. Their first language is English, but they are learning Portuguese. Their mother believes in food therapy, so she follows a very strict diet to help her children.

The last family I talked to was also introduced to me by another student of mine. In this case the children are also twins. They are a boy and a girl aged 3. In this specific case, autism was only suspected in the boy. The girl has just been observed, but the doctors still do not have an answer. This family focuses on behavior therapy.

Talking to different people was a highly important aspect in my research, because it gave me a broader view of Autism Spectrum Disorder. I could realize the effect of individuality within the syndrome. I already knew, due to my own experience, that one child is not like another child. Each one has a different development and difficulties. However, I was not aware that each family appears to react to the problem in different ways. My research helped me understand that we tend to follow what we believe in and what makes us feel well. As I pointed out earlier, the three families with ASD children mentioned in this paper did not chose the same treatments. What appears to be positive for one person may not be good for the other.

The last conversation I had was with the twins' father. Talking to people about this problem is not easy, and I am not referring to outsiders, but family. I noticed that I am not yet open to criticism or suggestions. I still do not know the reason for such resistance, since I consider myself an open-minded person. It is possibly because I am afraid of getting frustrated with different opinions. I also know that I might have to talk to our relatives and close friends at any moment, but as I said before, it is not easy. The only person inside my family I was convinced to talk to was my husband.

During our conversation, I said I wanted to know what it was like for him to have two ASD children. Once again I was surprised. He said it was not as difficult as it seems and said that he never had the feeling he was denying the situation. I believe he said that because once I had commented at home that I thought our

close relatives and friends did not accept the idea that the boys were different. He also said he did not remember how the process began, but since they were diagnosed he had tried to understand what to do to help them. The children were born with 37 weeks and since their first day at home our life got very difficult. They did not sleep more than one hour in a row. For this reason he did not remember when autism started to be an option. Everything was so complicated and we were so tired that deep inside we knew that something was different. But even in this situation we did not use dialog to help us get stronger and face the challenge.

It seems that our conversation was very short, which suggests that probably it may continue at another moment. Maybe it can occur in the future when I am not as afraid of talking to people as I am now. I need to leave my preconceptions about him and others. I do not want to face judgment, but I myself have judged people all the time. I supposed that what they may have to say would not help in the process. After all this reflection, I need to organize my ideas and let things flow naturally – talking when the situation requires and being firm when I believe it is necessary. Discernment is important to help me during this ongoing process.

Curiosities also happened during this study. My boys were sent to different therapies with different kinds of professionals and many of them did not seem surprised when I said my children also speak English. It seems common for ASD children to be able to speak foreign languages. The professionals said it may be their way of escaping, so it is common to have ASD children that are able to learn from the internet or even songs. After looking for a school for my children, I found one that accepted us. It was not simple and I had to appeal to the “Sétima CRE”, in order to solve a situation which they called “a problem with the computer system”. What really matters is that in my new boys’ school, there is another ASD child and he also speaks a little bit of English and his family did not know anything about it. Their teacher said that they were going to speak only Portuguese in a few months, but what I have seen up to now is their classmates speaking English when trying to imitate them. In Mother’s day celebration, I could hear children saying “oh my God” and “O dear!” These expressions are very common in my routine at home. This would be considered in further observation processes, since I have noticed children considering the way they speak to be important and copy them very often.

Even my colleagues started sending me messages with articles about Brazilian children who are able to speak a second language. Some short articles can be found on the internet, but not academic ones.

I intend to continue this study because I believe there is a call for further research in this area, as not much has been explored, mainly in Brazil. As a mother I do not find information easily to help me and as a teacher very little is discussed about in our pedagogical environment.

After all this enlightening experience, not only with this research paper but also as a mother I could understand why the symbol of autism is a puzzle. Like this research paper, which started with a puzzle, autism starts with a lot of different pieces that need to be put together to create a bigger picture. Putting the pictures together is not easy and demands time and effort and you only will be able to understand an ASD child if you look at the pieces carefully. In addition to this, ASD children have very different pieces creating different puzzles, making each ASD child unique and special.

References

ALLWRIGHT, D. Planning for Understanding: A new approach to the problem of method. *Vivenciando a Escola*, 7-24, 2003

BETTELHEIM, Bruno. *Love Is Not Enough: The Treatment of Emotionally Disturbed Children*. Glencoe, Ill.: Free Press, 1950.

BETTELHEIM, Bruno. *The Empty Fortress: Infantile autism and the birth of the self*. New York: The Free Press, 1967.

CALLAZANS, Roberto; MARTINS, Clara Rodrigues. Transtorno sintoma e direção do tratamento para o autismo. *Estilos Clín*, São Paulo, vol.12 n.22, 2007.

LÓPEZ, Macías; CELESTE, Silvia; ORQUERA, Cadena; RÓMULO, Marco. Inclusión laboral de personas con capacidades especiales (discapacidad) en las instituciones de salud del IESS de la provincia de Manabí desde febrero del 2013 a febrero del 2014. Available at: <http://dspace.udla.edu.ec/bitstream/33000/6212/1/UDLA-EC-TEAIS-2016-04.pdf>. Accessed 4 September 2017.

LORD, Catherine; COOK. H.; Edwin L. Bennett. AMARAL, David G. Autism Spectrum Disorders. *Neuron*, vol. 28, p.355-363, 2000. Available at: <http://www.sciencedirect.com/science/article/pii/S089662730000115X> Accessed 4 September 2107.

MAINARD, Diogo. *A Queda*. Rio de Janeiro – São Paulo Ed. Record. 2014.

MARINOVA-TODD, S. H.; MARSHALLI, D. B. & SNOW, C. E. Three misconceptions about age and L2 learning. *TESOL Quarterly*, vol. 34, p. 9-34, 2000.

OHASHI, Jeniffer Kaori. Comparing early language development in monolingual exposed and bilingual exposed young children with autism. University of British

Columbia, 2011. Available at:
<https://open.library.ubc.ca/media/download/pdf/24/1.0071722/1> accessed 4
September 2017.

PARK, Soyoung. Bilingualism and Children with Autism Spectrum Disorders: Issues, Research, and Implications. *NYS TESOL Journal*, vol. 1 no. 2 , 2014.
Royal Society of Medicine, England 2014 Available at:
<https://pdfs.semanticscholar.org/d675/56deb3f90905cdc76591aeca933960b2ef79.pdf> Accessed 4 September 2017.

TAGER-FLUSBERG, Helen. RHEA, Paul. LORD, Catherine. Language and communication in Autism, In *Handbook of Autism and Pervasive Developmental Disorders, Volume 1, Third Edition* (eds F. R. Volkmar, R. Paul, A. Klin and D. Cohen), John Wiley & Sons, Inc., Hoboken, NJ, USA. doi: 10.1002/9780470939345.ch12

Appendix

Songs

| | |
|---|---|
| <p>The itsy bitsy spider Went up the water spout Down came the rain And washed the spider out Out came the sun and Dried up all the rain And the itsy bitsy spider Went up the spout again!</p> | <p>A Dona Aranha Subiu pela parede, Veio a chuva forte e a derrubou. Já passou a chuva e o sol está surgindo e a Dona Aranha continua a subir. Ela é teimosa e desobediente. Sobe,sobe, sobe e nunca está contente.Olha a Dona Aranha aí gente. Domínio Público</p> |
|---|---|

| | |
|---|--|
| <p>Old MacDonald had a farm, E-I-E-I-O. And on his farm he had a cow, E-I-E-I-O. With a "moo-moo" here and a "moo-moo" there. Here a "moo" there a "moo" Everywhere a "moo"! Old MacDonald had a farm, E-I-E-I-O. Old MacDonald had a farm, E-I-E-I-O. And on his farm he had a pig, E-I-E-I-O. With an "oink" here and an "oink" there. Here an "oink" there an "oink"</p> | <p>Seu MacDonald tinha uma fazenda iaiaoh E em sua fazenda tinha uma vaca, iaiaoh Com um "moo-moo" aqui e um "moo-moo" lá. Aqui, um "moo" Existe um "moo" Em toda parte um "moo"! Seu MacDonald tinha uma fazenda, iaiaoh E em sua fazenda tinha um porco, iaiaoh Com um "oink" aqui e um "oink" lá. Aqui um "oink" Existe um "oink " Em toda parte um "oink"</p> |
|---|--|

| | |
|--|--|
| <p>Everywhere an "oink"! With a "moo-moo" here and a "moo-moo" there. Here a "moo" there a "moo" Everywhere a "moo"! Old MacDonald had a farm, E-I-E-I-O. The other animals on old MacDonald's farm are: a duck (quack-quack) a dog (wouw-wouw) a sheep (bah-bah)</p> | <p>Seu MacDonald tinha uma fazenda, iaiaoh Com um "moo-moo" aqui e um "moo-moo" lá. Aqui, um "moo" Existe uma "moo" Em toda parte um "moo"! Seu MacDonald tinha uma fazenda, iaiaoh Os outros animais na antiga fazenda MacDonald são: Um pato (quackquack-) Um cão (au-au) Uma ovelha (bah-bah)</p> |
|--|--|

Thomas and Friends Alphabet song

A is for Anne, B is for Bill and Ben, C is for Charlie, D is for Diesel Ten, E is for Emily, F is for Flynn, G is for Gordon, H is for Harvey, I is for Iron Bert, J is for James, K is for Kevin, L is for Lady, M is for Mavis, N is for Neville, O is for Oliver, P is for Percy, Q is for Quarry, R is for Reneas, S is for Salty, T is for Thomas, U is for up and away Percy, V is for Victor, W is for Wellworth, X is for X-ray and Z is for Zoo.