6-2016

Diagnostic Practices of Autism Spectrum Disorders in Brazil

Ana Claudia Vesper Manier Dias
Andrews University, diasa@andrews.edu

ABSTRACT

DIAGNOSTIC PRACTICES OF AUSTISM SPECTRUM DISORDERS IN BRAZIL

by

Ana Claudia Vespa Mainer Dias

Adviser: Luana Greulich

ABSTRACT OF GRADUATE RESEARCH

Thesis

Andrews University

School of Education

Title: DIAGNOSTIC PRACTICES OF AUSTISM SPECTRUM DISORDERS IN BRAZIL

Name of researcher: Ana Claudia Vespa Mainer Dias

Name and degree of faculty chair: Luana Greulich, PhD

Date completed: June 2016

In Brazil, in spite of over half a million students with special needs in primary education, little research has been conducted about ASD diagnostic practices. This involves learning about the training that professionals are receiving, what diagnostic practices are being implemented on the field, and whether those are being contextualized according to the Brazilian culture. Students with special needs are directly affected by the results of diagnostic practices, since identifying the individuals is one of the first steps. Lack of understanding about that stage may lead to the problematic realities of underidentification or overidentification, exclusion of children who should receive that special intervention and inclusion of some who do not need them. Precision in diagnosis, that considers cultural factors, is a highly desired and continuous goal for special

educators. Therefore, students with ASD are directly affected by the results of this research.

The purpose of this study is 1) to determine the knowledge and training of professionals that diagnose Autism Spectrum Disorder in Brazil (Audiologists, Neurologists, Pediatricians, Psychologists, Psychiatrists, and others), 2) to determine if those professionals are using diagnostic practices similar to the US, 3) to investigate which procedures and instruments are used in the diagnosis of a child suspected of having an Autism Spectrum Disorder in Brazil; and 4) to determine what happens after diagnosis.

This research can be placed within the context of studies focused on three complementary areas: conceptual, historical, and cross-cultural. The first area is related to the overall conceptual understanding of cultural factors in the diagnosis of ASD. The second one considers the historical influences in the diagnostic practices of children with ASD in Brazil, including government policies. The last one adopts a cross-cultural approach to the study of autism with emphasis on comparative studies.

The survey instrument specifically designed for this study is The Autism Spectrum Disorders Assessment Survey comprised of thirteen questions (single and multiple choice items, and Likert-type items) designed to collect information in regards to demographic characteristics of the participant, description of the diagnostic team, procedures, instruments used for diagnosis, and knowledge about characteristics necessary to identify a child as having an ASD. The survey received 236 responses from professionals that diagnose Autism Spectrum Disorders from every state and the Federal District in Brazil.

The results of this research suggest the need to invest in the training of professionals. Another related suggestion is to develop specific criteria and common diagnostic protocol for professionals in Brazil. Finally, providing access to inclusive education to people with autism would also provide them a more adequate opportunity for development.

Andrews University

School of Education

DIAGNOSTIC PRACTICES OF AUSTISM SPECTRUM DISORDERS IN BRAZIL

A Thesis

Presented in Partial Fulfillment

of the Requirements for the Degree

Master of Arts

by

Ana Claudia Vespa Mainer Dias

2016

DIAGNOSTIC PRACTICES OF

AUSTISM SPECTRUM DISORDERS IN BRAZIL

A thesis
presented in partial fulfillment
of the requirements for the degree
Master of Arts

by

Ana Claudia Vespa Mainer Dias

APPROVAL BY THE COMMITTEE:

_____
Rudolph Bailey, Ph.D., Chair

_____
Luana Greulich, Ph.D.

_____ _____
Jimmy Kijai, Ph.D. Date approved

TABLE OF CONTENTS

LIST OF ILLUSTRATIONS

LIST OF TABLES

LIST OF ABBREVIATIONS

ABA	Applied Behavior Analysis
ABN	Associação Brasileira de Neurologia
ABP	Associação Brasileira de Psiquiatria
ABRA	Brazilian Association for Autism
ADI	Autism Diagnostic Interview
ADI-R	Autism Diagnostic Interview-Revised
ADL	Language Development Assessment
ADOS	Diagnosis of Autism Observation System
AGF	Global Assessment of Functioning
AMA	Association of Friends of Children with Autism
ASD	Autism Espectrum Disorders
ASQ	Autism Screening Questionnaire
ATEC	Autism Treatment Evaluation Checklist
CAPS	Centro de Atenção Psicossocial
CARS	Childhood Autism Rating Scale
CARS-BR	Childhood Autism Rating Scale into Brazilian Portuguese
C-GAS	Children Global Assessment Scale
CHAT	Checklist for Autism in Babies
CENESPI	Centro de Estudos de Psiquiatria Integrada
CRP	Conselho Regional de Psicologia

DSM	American Psychiatric Association
ERIC	Education Resources Information Center
FADA	Fundação de Apoio e Desenvolvimento do Autista
ICD	World Health Organization
IDEA	Individuals with Disabilities Education Act
M-CHAT	Modified-Checklist for Autism in Toddlers
PDD	Pervasive Developmental Disorders
PECS	Communication System
PEP-R	Psychoeducational Profile-Revised
PTS	Single Therapeutic Project
SBNp	Sociedade Brasileira de Neuropsicologia
SBP	Sociedade Brasileira de Psicologia
SCIELO	Scientific Electronic Library Online
SCQ	Social Communication Questionnaire
TEACHH	Treatment and Education of Autistic and Communication Handicapped Children
UNASP	Brazil Adventist University
US	United States
WAIS-III	Wechsler Adult Intelligence Scale
WISC-III	Wechsler Intelligence Scale for Children

ACKNOWLEDGMENTS

Words certainly cannot express my joy and gratitude related as this research marks an important academic milestone in my life. First and foremost, I thank God for my relationship with Him and for His revelation, which has helped develop a holistic view of humanity and education, including special education.

I thank my husband, Marcelo, who taught me the true meaning of persistence and determination in a very special and loving way. His support in difficult times gave me strength and courage to go on. I love you so much!

I thank my daughter, Alissa Lauren, who unawarely inspired me every day to seek understanding and knowledge about child development and education as I watched her grow up (she is six years old).

I thank my parents, parents-in-law, and other family members and friends who offered support and love through emails, Facebook messages, phone and Skype calls from Brazil. A special mention to my deceased sister, Alessandra, who developed a type of leukodystrophy at the age of five, and certainly made me more sensitive and interested in people's special needs.

I thank Brazil Adventist University (UNASP), through its visionary president, Elder Paulo Martini, for sponsoring my graduate studies at Andrews University.

I thank all my previous students and colleagues who challenged me to continue looking for answers to the challenges of the noblest task of education and all

professionals who responded to the survey without which this research would not have been possible.

Finally, I thank my teachers and advisors at Andrews University. Dr. Rudolph Bailey, chair of the School of Education; Dr. Gabriel, who encouraged me from the very beginning and offered his support throughout the MA program; Dr. Kijai, director of the Educational Psychology graduate program, who offered his patience and expertise for this research; and Dr. Greulich, who believed in this project and offered her guidance throughout it. One of her most important contributions to my professional development was her example as a person and as an educator. I share with all of you my joy and gratitude.

CHAPTER I

INTRODUCTION

Psychiatrist Leo Kanner (1943) first identified autism in one of his studies. He observed 11 children (3 girls and 8 boys, between 2.5 and 8 years old) with an innate abnormality in social behavior, which included communication issues such as echolalia and a strict adherence to sameness. Kanner called this withdrawal, "extreme autistic aloneness." While his article on autism was published in 1943, autism did not become diagnosable and receive its own category until 1980, in the Diagnostic and Statistical Manual - Third edition (American Psychology Association, 1980).

A definition of autism is supplied by the Individuals with Disabilities Education Act (IDEA) as being a

> Developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. (U.S. Department of Education, 2004)

The fourth edition of the DSM (used in this study) has grouped those behavioral characteristics, such as social impairments, difficulties in verbal and non-verbal communication, restrictive, repetitive behaviors and stereotyped patterns of behavior, into five categories: Autistic Disorder, Pervasive Developmental Disorder, Asperger's Syndrome, Rett's Disorder and Childhood Disintegrative Disorder. These disorders are commonly referred to as Autism Spectrum Disorders (ASD).

ASD are identified by somewhat culturally-defined difficulties in social interaction, problems in verbal and nonverbal communication, and repetitive behaviors (Smith, 2004, p. 420). Those categories of symptoms are believed to be similarly present "in children across different cultures, but the meaning attributed to particular symptoms, help-seeking behavior, the degree that researchers and clinicians in different cultures follow the international diagnostic criteria, and available treatment options may vary greatly." (Kang-Yi, Grinker, & Mandell, 2013). Grinker (2007) points out that "autism, like all disorders, does not exist outside of culture. It is culture that sees something as abnormal or wrong, names it, and does something about it, and all cultures respond to illness differently" (p. 12). Because different cultures have different expectations about child behavior, "what is considered healthy behavior in one society may be viewed as unhealthy in another," the identification of disorders varies (Gardiner & Kosmitzki, 2008, p. 266).

Cultural factors have been associated with disparities in the prevalence of ASD due to overidentification or underidentification in the diagnosis of autism. In the United States, where there could be an overidentification of ASD, in 2007, the Center for Disease Control and Prevention reported that the prevalence of ASD was about 1 in 50 children. This figure reflects data from national studies, which revealed that the prevalence rates of ASD were 10 times higher than those reported in the 1980s and 1990s (Smith & Tyler, 2010, p. 415). Examples of underidentification are given by Grinker (2007) who compared different cultures and found out that autism was not seen as a disorder in France until 2004, while in Central Africa, children with autistic behavior are believed to be under attack by the family's ancestors. Another common misperception

that leads to underidentification is the fact that "symptoms frequently observed in children with ASD, such as hyperactivity and behavioral, can lead clinicians to diagnose attention deficit/ hyperactive disorder instead of ASD," an issue that has been linked to significant racial/ethnic disparities that exist in the diagnosis of ASD (Mandell et al., 2009, p. 493). Therefore, culture influences behavior expectations, and consequently, the diagnosis of autism.

While both, overidentification and underidentification, could be problematic, it seems that it is underidentification that causes more concern since it does not lead to proper care and intervention. At the core of this issue are diagnostic practices. "Programs for children in general (e.g., universal screening for autism) and programs that target traditionally underserved groups of children, their families, and their health care providers should be tested and implemented to optimize case finding of children with autism and to eliminate disparities" (Liptak et al., 2008). Paula, C. S., Ribeiro, S. H., Fombonne, E., and Mercadante, M. T. (2011) highlight the fact that the influence of cultural, ethnic, geographic and socioeconomic factors associated to Pervasive Developmental Disorders (PDD) is unclear. "Most surveys were conducted in North America, Northern Europe and Japan, and cross-national comparisons have been scarce (p. 1738).

In literature, there are many ideas in terms of best practices for diagnosing autism. Many articles describe this process sharing the idea of using a combination of observation, interviews, and rating scales for diagnosis. Thomas and Grimes (2002) point out the importance of the reliance on well-trained and experienced professionals and suggests the acronym "RIOT," which stands for review, interview, observe and test as the

procedures to follow. In the latest edition, no section on diagnostic practices is found, but there is one on interventions (Thomas & Grimes, 2008). Wilkinson (2010) recommends the use of a multidisciplinary team before arriving at any conclusion regarding a diagnosis. School professionals, doctors, and parents should be involved in developing a complete profile of the child based on records, interviews, and tests to ensure a correct diagnosis. Along the same lines, Matson used the identical guidelines for assessing autism in his book (Matson, 2008). Schwartzman emphasized the necessity of an extensive and comprehensive research protocol in each case (Schwartzman, 2003, p. 71).

Only recently, have researchers in Brazil begun mapping and studying the incidence of autism. There are no official statistics about the incidence of ASD in the general population in Brazil. The first study about epidemiology of Autism in Brazil was conducted in 2010 led by psychiatrist Marcos T. Mercadante in one town. His survey revealed a prevalence of one case of autism to 368 children between 7 and 12 years old (Paula et al., 2011). Another estimate dated of 2007 suggested as many as one ASD case per 190 inhabitants (Junior, 2010). Autism in Brazil seems to be following the growing trend of the West that has caused this disorder to be referred to as an epidemic and although a myriad of research studies on the disorder have been completed, ASD is far from being completely understood.

In practice, these dynamics are reflected in the differences of approach by private and public schools. In Brazil, traditionally, private schools have been better prepared to offer special education. There is no lack of critique to the inadequate public policies in the country. A recent study points out an example of a barrier to the improvement of the assistance to autist children: distribution of funds by the government to organizations

without clear proposals of detailed action (Mello, Ho, Dias, & Andrade, 2013, p. 75). Costa (2013) also points to the neglect by Brazilian authorities in regard to public policies for people with autism, specialized schools, and healthcare professionals, so the population can have an early diagnostic and a treatment with efficiency and dignity (p. 72).

As Mendes (2006) points out "access to education for children with special needs has been very slowly conquered as the educational opportunities for the general population are expanded" (p. 387). Furthermore, he identifies other needs even for those who have access to special education, such as lack of qualified professionals or resources in general. Also, "there are evidences of lack of interest by the government, a tendency to privatize...and a slow evolution in the number of applications [for special education students] accepted in comparison to the existent demand" (Mendes, 2006, p. 397). According to official numbers of Brazil's government, in 2012, private schools had a total of 178,589 special students (141,431 in exclusive classrooms or schools and 37,158 in regular classes) and public schools received a total of 641,844 special students (58,225 in exclusive classrooms or schools and 583,619 in regular classes) (*Brasil tem 40,3 milhões de estudantes na rede pública, diz Censo Escolar,* 2013*).*

Little research has been conducted in Brazil about ASD diagnostic practices. In 2011, Brazilian Association for Autism (ABRA, in Portuguese) and Association of Friends of Children with Autism (AMA, in Portuguese) conducted a survey on the state of autism in Brazil among 106 institutions. AMA is the largest support group for autism in Brazil founded in 1983 as a non-profit charity. The results of this survey provide initial understanding about autism in Brazil. For example, they estimated about 1.2

million people with autism who would need 40.000 institutions to assist them. In terms of diagnosis, interviews with the family (of social or psychological nature) was an early form of screening often quoted. Evaluations by a multidisciplinary team, which may include speech therapists, physiotherapists, psychologists, teachers, social workers were also mentioned. Assessment and diagnostic tests are also used. However, the study does not determine how institutions use these assessments to develop an intervention strategy. Of the 106 institutions, only 51 (48%) require a diagnostic report for admission. 52% of the institutions reported a lack of training for professionals to deal with autism, 13 institutions mentioned the need to improve access to specific vocational training for people with ASD, including professionals involved in the diagnostic process. The lack of understanding about autism and how to deal with it has led many professionals to make mistakes in their diagnosis and interventions. Among the recommendations by the researchers is the fact that, given the importance of diagnosis and the possibility of errors inherent to an incorrect diagnosis, it would be important to discover the cause of this trend and how to ensure that children with autism receive appropriate diagnosis (Mello et al., 2013).

In the Brazilian context, where autism is diagnosed outside the school system, Bragin (2011) supports the conclusions of the AMA's survey and concludes that there is a lack of technical guidance, monitoring, and evaluation of educational programming. Jorge (2003) points out the need for more research to qualify the evaluative process in his Master's thesis about instruments of evaluation of autistic children. Silva and Mulick (2009) discuss copying diagnostic models implemented in other countries and also highlight the large lacuna in terms of knowledge and professional empowerment in

relation to diagnostic practices. “Many children, especially in Brazil, remain for many years without a diagnostic or with an inadequate diagnostic” (p. 118).

Clearly, this is an inviting context for research that will shed light on the actual scenario of autism in Brazil. More specifically, besides other matters, there is a need to understand how the diagnostic of those children are being done. This involves, among other things, learning about the training that professionals are receiving, what diagnostic practices are being implemented on the field, and whether those are being contextualized according to the Brazilian culture. “Despite the renaissance in international autism research, there has been little attention to the effects of cultural context on the presentation, diagnosis and treatment of ASD” (Kang-Yi et al., 2013, p. 503). That type of research seems even more relevant in a social context as the Brazilian society, which has gone through a major redefinition in recent times.

Statement of the Problem

In order to correctly identify and adequately intervene, children with ASD need to be submitted to appropriate diagnostic practices. In spite of what seems to be an epidemic of autism in Brazil, unfortunately, very little research has been conducted about ASD diagnose, in general, and especially including the influence of cultural factors. There is little hope for this situation, unless the reality of ASD diagnostic practices in Brazil is surveyed, including the tools employed by professionals and their recommendations for children with ASD.

Purpose of the Study

The purpose of this study is 1) to determine the knowledge and training of professionals that diagnose Autism Spectrum Disorder in Brazil (Audiologists,

Neurologists, Pediatricians, Psychologists, Psychiatrists, and others), 2) to determine if those professionals are using diagnostic practices similar to the US, 3) to investigate which procedures and instruments are used in the diagnosis of a child suspected of having an Autism Spectrum Disorder in Brazil; and 4) to determine what happens after diagnosis.

Only recently, have researchers in Brazil begun mapping and studying the incidence of autism. Little research has been done in Brazil in order to reflect on cultural factors in the diagnostic of autism. Much of the material used in that process has been developed in other countries, such as the United States. Besides that, even though, culture is not a static element of a society, recently, Brazil has been going through a major redefinition of its social context.

Research Questions

The research questions for this study are:

1. What are the knowledge and training of professionals that diagnose Autism Spectrum Disorder in Brazil (Audiologists, Neurologists, Pediatricians, Psychologists, Psychiatrists, and others)?
2. What are the diagnostic practices of children with ASD in Brazil?
3. What are the tools used to diagnose children with ASD in Brazil?
4. What happens after diagnosis?

Importance and Significance

In Brazil there are over half a million students with special needs in primary education. Students with special needs are directly affected by the results of diagnostic practices, since identifying the individuals is one of the first steps. Lack of understanding

about that stage may lead to the problematic realities of underidentification or overidentification, exclusion of children who should receive that special intervention and inclusion of some who do not need them. Precision in diagnosis, that considers cultural factors, is a highly desired and continuous goal for special educators. Therefore, students with ASD are directly affected by the results of this research.

This study will advance the existing small body of knowledge about ASD diagnostic practices in Brazil, the tools used in those practices, and what follows the diagnostic. It will also help identify whether contextualization has been part of the process. By expanding the field of educational psychology, this research will encourage new initiatives to improve current practices.

Limitations and Delimitations

This research will be primarily limited by the availability of research on autism in Brazil. The limited knowledge about cross-cultural differences in special education will also be a limitation. Finally, besides time constraints, there will be some limitations related to the method of data collection, self-survey, used in this study.

This research is delimited geographically to the country of Brazil as the main area of study and the United States as object of comparison. Another delimitation is the choice of, among different emotional and behavioral disorders, ASD as the focus of this study.

Conceptual Framework

The challenges of diagnosing ASD across different cultures seem to be even more relevant for research in times of globalization as the 21st century. This research is found within the category of descriptive research. This research can be placed within the context of studies focused on three complementary areas: conceptual, historical, and

cross-cultural. The first area is related to the overall conceptual understanding of cultural factors in the diagnosis of ASD. The second one considers the historical influences in the diagnostic practices of children with ASD in Brazil, including government policies. The last one adopts a cross-cultural approach to the study of autism with emphasis on comparative studies.

Cross-cultural studies are interested with the prevalence or frequency of a specific trait, the causes of a trait or custom, the consequences or effects of a particular trait or custom, and possible associations with other cultural aspects. This study will use field data to describe practices of professionals involved in the diagnostic of children with ASD in Brazil. By sampling the population of professions and surveying them through self-survey, the researcher will be able to collect data and describe their traits.

CHAPTER 2

LITERATURE REVIEW

Purpose of Literature Review

The objective of this review is to gather and analyze selected scholarly work relevant to the discussion on the diagnostic of ASD in Brazil. It also provides a context for this research and demonstrates where it fits into the existing body of knowledge. Autism spectrum disorders are identified primarily by difficulties in social interaction, problems in verbal and nonverbal communication, and repetitive behaviors (Smith, 2010, p. 420). This literature review focuses on recent studies, models, statistics, and case studies. These include academic research on the knowledge and training of professionals who diagnose children with ASD, diagnostic practices, instruments used to diagnose, and what happens after that, conducted especially in Brazil. There are nine references with Brazilian authors and two Master theses among the literature reviewed.

In order to correctly identify and adequately intervene, children with ASD need to be submitted to appropriate diagnostic practices. In spite of what seems to be an epidemic of autism in Brazil, unfortunately, very little research has been conducted about ASD diagnose, in general, and especially including the influence of cultural factors. There is little hope for this situation, unless the reality of ASD diagnostic practices in Brazil is surveyed, including the tools employed by professionals and their recommendations for children with ASD.

Criteria

In order to have a broad understanding of the literature on this topic, ERIC databases were searched using terms such as “autism,” “practices,” “tools”, “after diagnosis” “Brazil,” “diagnostic,” and their combinations. The same terms were used in searching EBSCO HOST for scholarly articles. The third search was conducted on the PsycINFO database. The Portuguese Google Scholar engine was also used to find studies in that language. Finally, Scielo Scientific Electronic Library Online was instrumental to have access to academic work produced in Brazil since this is one of the most used databases in Brazil. The criteria for inclusion and exclusion of the material found included date of publication and direct relation to the subject. Studies older than ten years were considered only if they had historical information. Another relevant consideration was the inclusion of studies done by Brazilian researchers in order to add an inside view of the issues involving the diagnostic of autism within that particular culture. Bibliographic research as part of a study also contributed to the inclusion of such researches. For the most part, the material included can be considered primary quantitative and qualitative literature. Secondary literature is used selectively.

Autism in Brazil

As Grinker (2007) points out, “autism, like all disorders, does not exist outside of culture. It is culture that sees something as abnormal or wrong, names it, and does something about it, and all cultures respond to illness differently” (p. 12). For example, comparing autism diagnosis in different cultures, he identifies that autism was not seen as a disorder in France until 2004, while in Central Africa, children with autistic behavior are believed to be under attack by the family’s ancestors.

Only recently, have researchers in Brazil begun mapping and studying the incidence of autism. It seems that the majority of the studies in special education have focused the issue of inclusion and government policies, especially from a historical perspective.

Most numbers are estimates considering the total or regional population and the world average prevalence reported by epidemiological studies (Mello et al., 2013, p. 41).

According to official numbers of Brazil's government, in 2012, private schools had a total of 178,589 special students (141,431 in exclusive classrooms or schools and 37,158 in regular classes) and public schools received a total of 641,844 special students (58,225 in exclusive classrooms or schools and 583,619 in regular classes) ("Brasil tem 40,3 milhões de estudantes na rede pública, diz Censo Escolar," 2013).

The first study about epidemiology of Autism in Brazil was conducted in 2010 led by psychiatrist Marcos T. Mercadante in one town. His survey revealed a prevalence of one case of autism to 368 children between 7 and 12 years old (Paula et al., 2011). Another estimate dated of 2007 suggested as many as one ASD case per 190 inhabitants (Junior, 2010). Autism in Brazil seems to be following the growing trend of the West that has caused this disorder to be referred to as an epidemic and although a myriad of research studies on the disorder have been completed, ASD is far from being completely understood.

In 2011, Brazilian Association for Autism and Association of Friends of Children with Autism conducted a survey on the state of autism in Brazil among 106 institutions. AMA is the largest support group for autism in Brazil founded in 1983 as a non-profit charity. The results of this survey provide initial understanding about autism in Brazil.

Besides information about the general presence of ASD in Brazil, literature about diagnostic practices in that country were considered. In order to help classify the academic sources, they have been divided into four categories according to the research questions.

Knowledge and Training of Professionals

The diagnosis of autism is based on a set list of criteria. In several countries of Europe and North America, including the United States and Canada, experts in the field recommend that the diagnosis be made based on the criteria established by the ICD-10 (World Health Organization., 1992) and/or the DSM-IV- TR (American Psychiatric Association, 2003).

According to the DSM-IV-TR, for a child to be diagnosed with autistic disorder, she should have at least six in the list of twelve symptoms listed in Table 1, with at least two of the symptoms should be in the area of social interaction at least one in the area of communication, and at least one area of restricted, repetitive and stereotyped behaviors.

Table 1.

List of symptoms of autistic disorder, by area, in accordance with criteria provided by DSM-IV-TR (American Psychiatric Association, 2003)

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

    1. Qualitative impairment in social interaction, as manifested by at least two of the following:
        a. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
        b. Failure to develop peer relationships appropriate to developmental level

Table 1—*Continued*

c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
d. Lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

2. Qualitative impairments in communication as manifested by at least one of the following:
   a. Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
   b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   c. Stereotyped and repetitive use of language or idiosyncratic language
   d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:
   a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   b. Apparently inflexible adherence to specific, nonfunctional routines or rituals
   c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   d. Persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

It is also necessary to identify conditions that coexist with a picture of autism. The condition most commonly coexists with autism is mental retardation, present in varying levels of severity in approximately 60-75% of children with autism (Bailey, Phillips, &

Rutter, 1996; Barbaresi, Colligan, Weaver, & Katusic, 2009). There are cases in which frames were identified as of autism in subjects coexisting with other disorders such as Down syndrome, cerebral palsy and Tourette syndrome, as well as visual and auditory deficiencies (Charman & Baird, 2002). Tables of depressive and anxiety disorders are also common in adolescents and adults with high cognitive functioning autism (Mash & Barkley, 2006, pp. 455-511).

Lack of knowledge about those criteria and autonomy on the part of health professionals are major hindrances in dealing with ASD disorders. One study shows that only 14.3% of autism patients have been referred to a partner institution for professionals. This research also reveals that knowledge about autism and psychosis, as well as the ability to diagnose and future routing, are concentrated in institutions, which indicates the need for investment in the training of health professionals, particularly infancy doctors (Visani & Rabello, 2012, p. 303).

Related to professionals' knowledge about ASD is the training available for and required of them. Four studies were selected in terms of their relevance to the current research that is characterized by a historical perspective. Bragin (2011) reflects on current teaching practices in specialized educational service centers in Brazil. The article focuses on the historical influences of government policies. One of Bragin's conclusions is that there is a lack of technical guidance, monitoring, and evaluation of educational programming in the Brazilian context.

The situation in Salvador, Bahia, may be an example of that situation. There is a small number of poorly prepared professionals available to advise the population. They are 365 psychiatrist and neuropediatricians to serve an estimated seven thousand autists.

“There is no possibility for an autist to study in a regular school in Salvador, due to the lack of training of teachers and the atypical behavior" of these patients (Social, 2013).

Because of that situation, several authors report on the need to implement a continued education program for professionals addressing the interaction specific situations (Felicio, 2007; Ludke, 2011; Montagner, Santiago, & Souza, 2007). In 2013 the federal government passed Law 12.764 establishing the National Policy for Protection of Rights of Individuals with ASD. Among the highlights of the policy is the participation of community in the formulation of public policies for people with ASD and the implementation of service centers, psychosocial monitoring and evaluation of public health care. A booklet was also released to guide health professionals in the diagnosis of autism (Tibyriça, 2013).

Local government initiatives are also being implemented in different places in order to address the lack of knowledge and preparation of professionals. Recently the government of Rio de Janeiro city has been analyzing a law project to establish professional training actions for the diagnosis and treatment of people with autism through the Municipal Health department. The goal, according to the author, is "to implement the necessary public policies, given the high prevalence of autism in our Municipality, as well as to promote appropriate multidisciplinary treatment respecting the differences, while seeking to promote social inclusion as determined by our legislation” (Câmara Municipal do Rio de Janeiro, 2014).

Diagnostic Practices

Among relevant studies about diagnostic practices, emphasis on the Brazilian context was given. Silva and Mulick (2009) discuss aspects regarding that criteria

following an approach based on diagnostic models implemented in other countries. They highlight the fact that there is a large lacuna in terms of knowledge and professional empowerment in relation to diagnostic practices and that "many children, especially in Brazil, remain for many years without a diagnostic or with an inadequate diagnostic" (p. 118).

The same conclusion is reached through the data obtained by Psychosocial Care Center Child. This study shows that the beginning of a treatment for children diagnosed with autism and childhood psychosis is later than expected. Three reasons are given: "missing the early detection; the delay on the part of institutions and/or health professionals in the diagnosis and carry out a referral; uncertainty in achieving a proper treatment of the disease by professionals and health institutions" (Visani & Rabello, 2012, p. 300). The methods available for the early detection of autism allow identifying traits of psychopathology in infants at three months of age. However, the data show that formal diagnosis, in the case of autism, happens at two years in 21.4% of cases; at three years, in 14.3%; at four years, in 28.6%; at five years, in 18.6%; and at six years, in 7.1% of cases (Visani & Rabello, 2012, p. 301). Several authors acknowledge that there is a great lack in proper and accurate diagnosis. The observation is that, in Brazil, "in several states, many children remain with a diagnosis open to ages 6 or 7 years and even longer" (Silva & Mulick, 2009, p. 118). The study by Rosenberg, Daniels, Law, Law, and Kaufmann (2009) about trends in autism spectrum disorder diagnoses between 1994 and 2007 analyzed predictors of parent-reported initial diagnosis among 6,176 individuals. They found that the "distribution of diagnoses was influenced by a secular time trend

factor.” Other significant factors included ethnicity, white race, geographic location, urbanicity, and, interesting enough, initial evaluator (p. 1099).

Silva and Mulick (2009) conclude that "professionals engaged in the practice area in several states in Brazil makes us believe that autism diagnostic practice currently implemented in many parts of the country still need better guidelines and general organization to become more effective” (Silva and Mulick, 2009, p. 128). Besides the government, among professionals, the responsibility seems to fall primarily on Pedriaticians, who “are the first health professional to come in contact with patients with autism. Thus, they should be able to diagnose and to coordinate the multidisciplinary treatment of these patients” (Gadia, Tuchman, & Rotta, 2004, p. 83). Early intervention in the context of autism not only increases the chances of treatment, but also minimizes some symptoms experienced by parents, compounded over time (Visani & Rabello, 2012, p. 295). It is suggested that it is also up to Psychologists, through the dissemination of knowledge, to contribute towards making the relationship between Pediatricians and mother/baby also a space for ASD evaluation (Laznik, 2000, p. 79).

Because the spectrum of presentations and clinical manifestations suggest a neurobiological heterogeneity within ASD, the clinical evaluation of all infantile autism cases should always appraise the neurological, psychiatric and genetic features (da Costa & Nunesmaia, 1998, p. 24). Therefore, the cooperation between Neurologists, Psychiatrists, Neuroscientists, Psychologists, Speech Therapists, Occupational therapists and Educators becomes crucial not only to boost the understanding of ASD and allow more appropriate management of patients throughout their lives, but also to allow a clearer view of the social being as a whole (Gadia et al., 2004, p. 91).

Diagnostic Instruments

The assessment of autistic individuals requires, besides a multidisciplinary team, the use of objective scales. In the 1980s, scales, questionnaires and criteria were developed in order to try to standardize the diagnosis of ASD. The Diagnostic and Statistical Manual of Mental Disorders, the AAP (American Psychiatric Association, 1987) became the most widely accepted. Since then, the fourth version was produced, as mentioned earlier, and, recently (2013), the fifth edition of the DSM was published presenting more detailed diagnostic criteria infantile autism (American Psychiatric Association & DSM Task Force, 2013; da Costa & Nunesmaia, 1998, pp. 24,25).

Besides those, there are several other systems used for the diagnostic of autism. Checklist for Autism in Babies (CHAT), developed by Baron-Cohen, Allen, and Gillberg, in 1992, is a scale for diagnostic of autism at 18 months of age. It is comprised of a set of nine questions with yes/no answers for the parents. (Mello, 2005, p. 24). Childhood Autism Rating Scale (CARS) consists of a structured interview of 15 items (can be applied in 30-45 minutes) with the parents of an autistic child 2 years age. Each of the 15 items is evaluated on a seven-point scale, which allows for classifying mild/moderate or severe forms of autism. The adaptive behavior scale of Vineland is another assessment tool commonly used, which has the potential to measure social development in a normal population. Two of the most comprehensive batteries of psychological tests used for the diagnosis of autism, particularly in research, is the Diagnosis of Autism Observation System (ADOS) and the Autism Diagnostic Interview (ADI). Together, they represent a complete structured interview and observation method to objectively assess the social skills, communication and behavior of autistic individuals,

ranging from children to adults without language able to communicate fairly well (Gadia et al., 2004, pp. 86, 87).

One of the main concerns about those instruments refers to their applicability and validity in different cultures. "The key question is whether we can infer that scores from such assessments have the same meaning for different ethnocultural populations" (Pereira, Riesgo, & Wagner, 2008a, p. 493). A literature review indicates experiments with three instruments in the Brazilian context.

Pereira et al. (2008a) have translated CARS into Brazilian Portuguese (CARS-BR) and determined the initial psychometric properties of the resulting version. The process involved backtranslation and evaluation of semantic equivalence. In order to determine its psychometric properties (internal consistency, validity and reliability), CARS-BR was administered to 60 consecutive patients with autism, aged between 3 and 17 years and seen at a university hospital. Results suggest that the CARS-BR is a valid and reliable instrument for evaluating autism severity in Brazil (p. 487).

Sato et al. (2009) report on a project to adapt another instrument for autism diagnosis. They translated the Autism Screening Questionnaire (ASQ) into Portuguese and validated it for use in Brazil. Their study involved 120 patients with a clinical diagnosis of pervasive developmental disorder, Down syndrome, or other psychiatric disorders. Their conclusion was that the final version of the instrument had satisfactory measurement properties, suggesting preliminary validation properties. A closer look at their method will reveal, however, that their adaptation to the Brazilian culture was limited to a professional bilingual translation with satisfactory "semantic, idiomatic and

cultural equivalence" (p. 31). No other cultural adaption was involved in that process of contextualization.

A recent Master's thesis by Becker (2009) considers a third instrument and its adaptation to the Brazilian context. The project evolved around translating the Autism Diagnostic Interview-Revised (ADI-R) into Portuguese and validating it. After a similar method of translation as the two previous studies mentioned, an interview was conducted with 20 autistic patients and 17 patients with mental disabilities. The results indicated a high internal validity and high external consistency. The researcher concludes that her study is useful in Brazil in spite of its small sample and restricted testing.

In terms of application of those instruments by professionals in the diagnostic of ASD in Brazil, Paula et al. (2011) conducted a pilot study based on a combination of standardized instruments and clinical evaluations by experts. An important contribution of that research is the observation of how the researchers handled the Autism Screening Questionnaires.

Finally, another relevant literature review is a Master's thesis about the instruments of evaluation of autistic children. Jorge (2003) maps those instruments based on 64 articles found in comprehensive academic databases. The results point to the need for more research, especially in Brazil, to qualify the evaluative process.

Post-diagnosis

Once the diagnosis of autism has been reached, the next steps have to be determined. This includes referrals to professionals such as occupational therapists, physiotherapists, speech therapists, neurologists, and geneticists. It also includes the child and the family. They should participate in specific educational programs (Silva &

Mulick, 2009, p. 128). “The role of professionals working with autism is similar to a cross-cultural interpreter or guide, someone who understands both cultures and is able to translate and guide expectations and procedures of the non-autistic environment for the individual with complex and extensive changes” (Kwee, Sampaio, & Atherino, 2009, pp. 217, 218).

In Brazil, institutions have adopted different intervention programs for treatment and education of children with autism, such as Treatment and Education of Autistic and Communication Handicapped Children (TEACHH), Natural Functional Curriculum, and Picture Exchange Communication System (PECS) (Giardinetto, 2005).

The TEACCH method uses an assessment called Psychoeducational Profile-Revised (PEP-R) to evaluate the child and develop a personalized intervention taking into account their strengths and their challenges. TEACCH aims to develop the child's independence and allows an interdisciplinary team to monitor individual students' progress (Kwee et al., 2009, pp. 224, 225). Two major criticisms of this method are related to applying it to children with high functioning and the possibility of turning those children into “robots” (Mello, 2005, p. 36).

Picture Exchange Communication System is a system primarily used with children who do not communicate. It is based on applying a sequence of six steps to help the child realize that through communication it can get very quickly the things you want. Advantages of this program include that its low demand of complex or expensive materials, relative easiness to learn, it can be applied anywhere and, when correctly applied, displays unquestionable results in communication through cards in children who

do not speak, and organization of verbal language in children who speak (Mello, 2005, p. 39).

Applied Behavior Analysis (ABA) is another widely used program in Brazil. This program aims at teaching the child skills they lack. Each skill is introduced in association with a statement or instruction. Repetition is an important point of this approach, as well as exhaustive record of all attempts and their results. The main criticism of the ABA is the ethical concern in terms of turning the child into a "robot." Another criticism of this method is that it is expensive (Mello, 2005, pp. 37, 38).

There are other forms of intervention such as psychotherapy treatments, speech therapy, equine therapy, and music therapy. The indication of those treatments "depend directly on the vision, the goals and the good sense of every professional who applies" (Mello, 2005, p. 40).

CHAPTER 3

METHODOLOGY

Research Design

This research was conducted in order to investigate the diagnosis of ASD in Brazil. The researcher utilized the descriptive method based on a quantitative non-experimental survey design. Descriptive research, widely accepted, seeks to discover a phenomenon and interpret it as accurately as possible in terms of its nature and characteristics (Certo & Bervian, 1996, p. 49). The purpose of employing this method is to describe instruments and procedures used the diagnosis of ASD in Brazil as well as the knowledge and training of professionals involved and what happens after that process. Considering the lack of research about this reality in Brazil, a descriptive research would contribute to the body of knowledge in that specific field.

This study employed quantitative approach focused on the numerical findings from the respondents. Among the advantages of this approach are the possibility of generalization, provision of numerical information, and mapping a phenomenon across groups and large geographic areas, as in this case. Objectively, that was conducted without direct manipulation of conditions experienced by participants employing a nonexperimental survey research design. Survey design research, commonly used in educational research, focuses on a sample of subjects and administers a questionnaire to collect data. One assumption is that information about the large population will be inferred from the smaller group of subjects (McMillan & Schumacher, 2010, pp. 22-23).

This study relies on primary data derived from the respondents' answers in self-administered questionnaires.

The Internet has provided a more practical medium to conduct survey research. Web-based surveys rely on online electronic surveys, e-surveys, email surveys, or Internet surveys, having in common the use of the Internet to send and receive the results. Individuals are invited to access the survey and submit their answers online. Web-based survey services are economical, easy to use for formatting the questionnaires, practical to manage respondents, and reliable to run reports. In general, advantages of online surveys include low cost, quick response, easy follow-up, and the ability to work with a large population (McMillan & Schumacher, 2010, pp. 240-241). Most disadvantages were avoided in this research. The group of respondents was formed by professionals, such as Psychologist, Neurologists, and Psychiatrists, who are Internet savvy. Information overload was not an issue because the survey was short. Confidentiality and privacy issues were avoided by using a reliable online service.

Population and Sample

The target population of this research is professionals that diagnose Autism Spectrum Disorders in Brazil. The North-American school system relies on a school psychologist as the primary professional to diagnose ASD. In Brazil, the professional responsible for educational development of students are not trained and licensed to do that. Their job is to refer students to other professionals, such as Audiologists, Neurologists, Pediatricians, Psychologists, and Psychiatrists.

Sampling will be a convenience sample based on contacts found through groups of professionals, associations, and institutions, including National Registry of

Professionals of Autism, Brazilian Association for Autism, Association of Friends of Children with Autism, Autismo & Vida, Autismo Infantil, Autismo e Intervenção, Autismo Integrado, Autismo e Realidade, Centro de Atenção Psicossocial (CAPS), Fundação de Apoio e Desenvolvimento do Autista (FADA), Psicobreve Psiquiatria e Psicologia, Centros de Neurologia Cadastrados na Associação Brasileira de Neurologia (ABN), Academia Brasileira de Neurologia, Sociedade Brasileira de Neuropsicologia (SBNp), Conselho Regional de Psicologia (CRP), Sociedade Brasileira de Psicologia (SBP), Psiquiatria Infantil.com.br, Associação Brasileira de Psiquiatria (ABP), Comporte-se Psicologia Científica, Mundo Psicólogos.com, Centro de Estudos de Psiquiatria Integrada (CENESPI), Brasil Psiquiatria, Psiquiatria Online, Centro de Atendimento Psicanalítico (SBPSP), Fonaudiólogas Fonoaudiologia, Fonoaudiólogos Associados, Fonoaudiólogos do Brasil, Conselho de Fonoaudiologia, Pediatria Brasil, and Sos Pediatria. In order to get a broader perspective on the diagnostic practices of ASD, the sample employed in this research includes individuals from every one of the 26 states of Brazil and the Federal District. The more populous and richer states, such as São Paulo and Rio de Janeiro, have a significant higher representation in the sample, which reflects the reality to an extent. Although the researcher believes that the sample is representative of the general population of professionals in Brazil, this is a non-probability sampling technique.

Instrumentation

The survey instrument specifically designed for this study is The Autism Spectrum Disorders Assessment Survey comprised of thirteen questions (single and multiple choice items, and Likert-type items) designed to collect information in regards

to demographic characteristics of the participant, description of the diagnostic team, procedures, instruments used for diagnosis, and knowledge about characteristics necessary to identify a child as having an ASD (see Appendix D).

This instrument was developed by Rudolph Bailey, Jeannie Montagano, Tevni Grajales, Brandon Tross, and Ron Coffen and has been applied to a similar study in the United States. The first nine questions were related to the professional practice of respondents. The rest of the questions were related diagnostic practice. A few adaptations were necessary. Question 1 was added to the survey in order to help describe the population with which professionals work the most. It surveys are, gender, and socioeconomic status. The researcher also added question 3 to identify which was the respondent's professional practice. The diagnostic of ASD in Brazil is not done by a school psychologist as in the United States, but by a number of other professionals, such as Psychologists, Psychiatrists, Neurologists, and Pediatricians, as previously discussed. In question 9 the researcher used a list of instruments or measures known in Brazil. The options followed the official Protocol of the State of São Paulo for Diagnostic, Treatment, and Referral of Patients with ASD (Tamanaha et al., 2013, p. 22). Respondents had the option to mention other instruments they might use. Question 10 was added to the questionnaire. It asks about interventions recommended by those professionals and considers what happens after the diagnosis. Finally, question 13 was an addition to the survey that sought information on who referred the students to receive a diagnostic.

This research was conducted in 2014. Between June 22nd and August 20th, the link to the online questionnaire (Web-based Internet survey) was sent to approximately 1,500

professionals by email and 580 by Facebook message. The survey received 236 responses from professionals from every state and the Federal District in Brazil. The anonymous nature of the survey helped to eliminate experimenter bias. Inviting professionals in every state in five different geographic regions to participate in the study allowed the result to be more generalizable to the greater population of professionals than if the participants were limited to specific predetermined regions and cities.

The researcher sent emails and Facebook messages with a link to the survey hosted online by Toluna QuickSurveys. The link directed the respondent to a cover letter and informed consent. After clicking on NEXT, the respondent is presented with the survey divided into four parts before the professional can submit his or her answers.

Data Analysis Procedures

The data collected in the quantitative approach, via online survey, were tabulated in spreadsheets and treated to enable comparisons and inferences. Figures and tables were used to present the results in a more comprehensive and meaningful way in most questions (See Chapter 4). Toluna QuickSurveys provide enough tools to select, cross, and display the information collected in the questionnaire.

CHAPTER 4

RESULTS

Knowledge and Training of Professionals

Findings from the Austism Spectrum Disorders Assessment Survey with 236 respondents portrayed the current situation in Brazil. The profile of the respondents was traced in questions 2 to 5. The sample had representation from all 26 states and the federal district (Q2). These were the states of the top five largest groups: São Paulo (27.97%), Paraná (12.71%), Rio de Janeiro (9.75%), Minas Gerais (8.05%), and Rio Grande do Sul (6.36%) (see Table 2).

Table 2

Q2. State in which you are employed.

	Total (% & freq col)	
	100.00% (236)	
Acre	0.42%	1
Alagoas	0.85%	2
Amapá	0.85%	2
Amazonas	0.85%	2
Bahia	5.51%	13
Ceará	0.42%	1
Distrito Federal	2.12%	5
Espírito Santo	0.42%	1

Table 2—*Continued*

Goiás	1.27%	3
Maranhão	1.27%	3
Mato Grosso	4.24%	10
Mato Grosso do Sul	0.85%	2
Minas Gerais	8.05%	19
Pará	1.27%	3
Paraná	12.71%	30
Paraíba	4.24%	10
Pernambuco	2.54%	6
Piauí	0.42%	1
Rio de Janeiro	9.75%	23
Rio Grande do Norte	0.42%	1
Rio Grande do Sul	6.36%	15
Rondônia	0.42%	1
Roraima	1.27%	3
Santa Catarina	4.24%	10
São Paulo	27.97%	66
Sergipe	0.42%	1
Tocantins	0.85%	2

As far as professional practice (Q3), the three largest groups of respondents were Psychologists (42.80%), Audiologists (25%), and others (20,34%), which included Educational Psychologists (3.37%), Occupational Therapists (2.76%), and Neuropsychologists (0.92%) (see Figure 1).

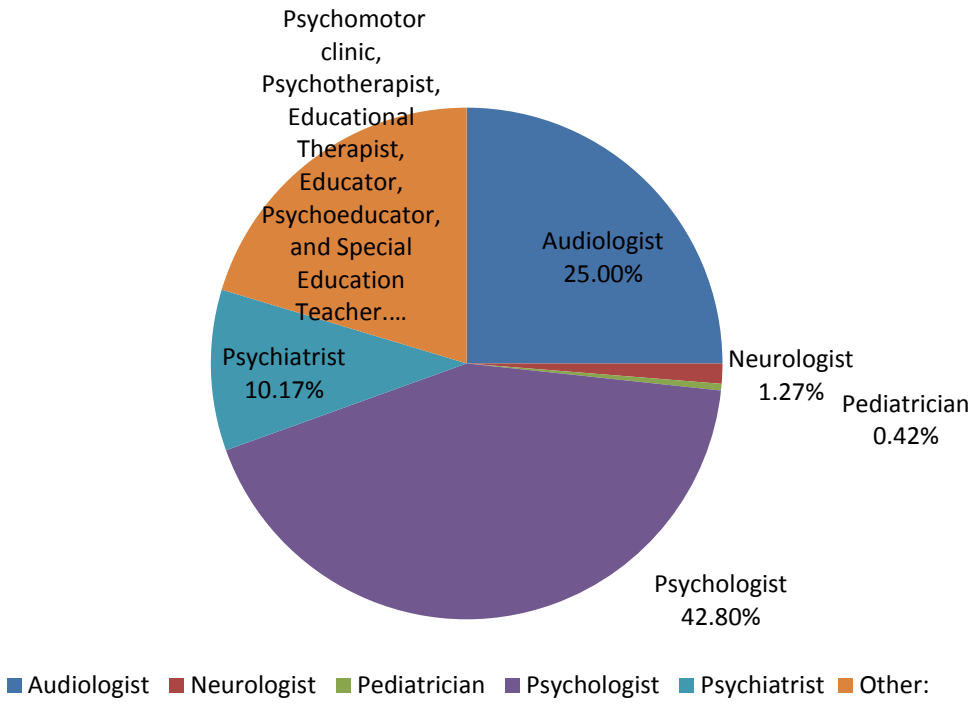


Figure 1. Answers to question 3 (Q3): Which is your professional practice?

The number of years of experience of those professionals varied (Q4) as following: 164 respondents marked that their time of experience was between 1 and 10 years; 53 respondents between 11 and 20 years; and, 19 respondents more than 20 years (See Figure 2).

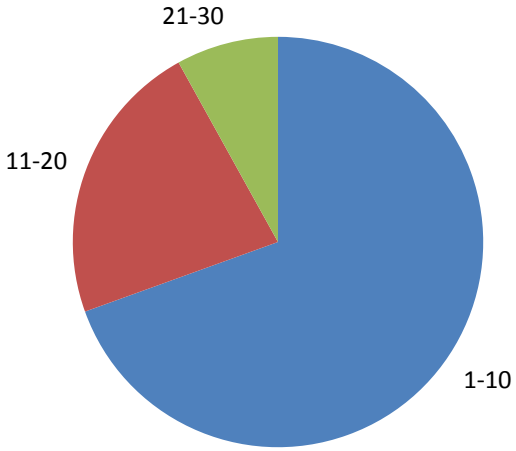


Figure 2. Answers to question 4 (Q4): Years of professional experience in this area.

Their experience also reflected on the number of children evaluated for possible ASD throughout their careers (Q5): 8 professionals reported between 500 and 3,500 evaluations, 34 professionals reported between 55 and 499 evaluations, 102 professionals reported between 10 and 54 evaluations, and 92 professionals reported between 0 and 9 evaluations (see Figure 3).

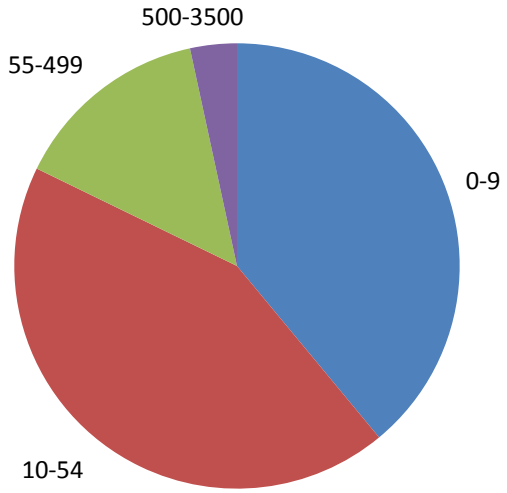


Figure 3. Answers to question 5 (Q5): Approximately how many children have you assessed for possible ASD (over your full career)?

A description of the population with which professionals work the most was found in the answers to the first question (Q1). They revealed that over 70% of the children diagnosed are between ages 1.5 and 10, being the segment between 5 and 10 years old larger (1.5 to 5, 31.78%; 5 to 10, 39.83%). The next largest group is above 25 years-old (11.86%) (see Figure 4).

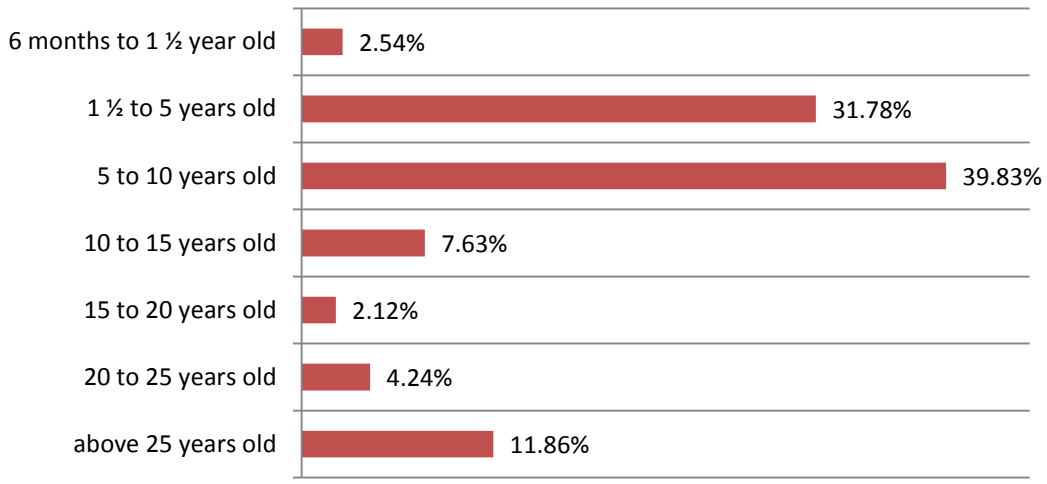


Figure 4. Answers to question 1a (Q1a) about the age of the population with which professionals work the most.

The majority of these children are from the middle class (58.9%), followed by the lower class (31.78%), and the upper class (9.32%). Regarding gender, there was a higher male prevalence of approximately 3.5 to 1 (see Figure 5).

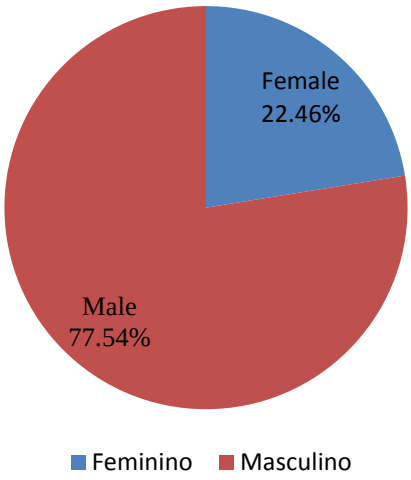


Figure 5. Answers to question 1b (Q1b) about the gender of the population with which professionals work the most.

In order to determine the knowledge and training of professionals who diagnose ASD in Brazil, the answers to questions 11 (Q11) and 12 (Q12) are relevant. As far as training received by those professionals, having the option to choose more than one answer, 83.90% of respondents indicated *read books and/or professional articles;* 66.53% marked *conferences, online seminars and/or workshops*; 47.88% checked *undergraduate course on ASD and other disorders*; and 44.92% indicated *graduate course with exclusive focus on ASD*. The option *other* (19% of respondents) included *Training to Administer ADI-R, CARS-BR, ABA, VB-MAPP, DOMAN, FLOORTIME, SON RISE, PECS, TEACCH; Specific course in the area of ASD; Practical Experience in a Specialized Clinic for Autism; Experience with Neurologists Experts in the Field of Autism; and Theoretical and Practical Course in the Association of Friends of Autistic (AMA)* (see Figure 6).

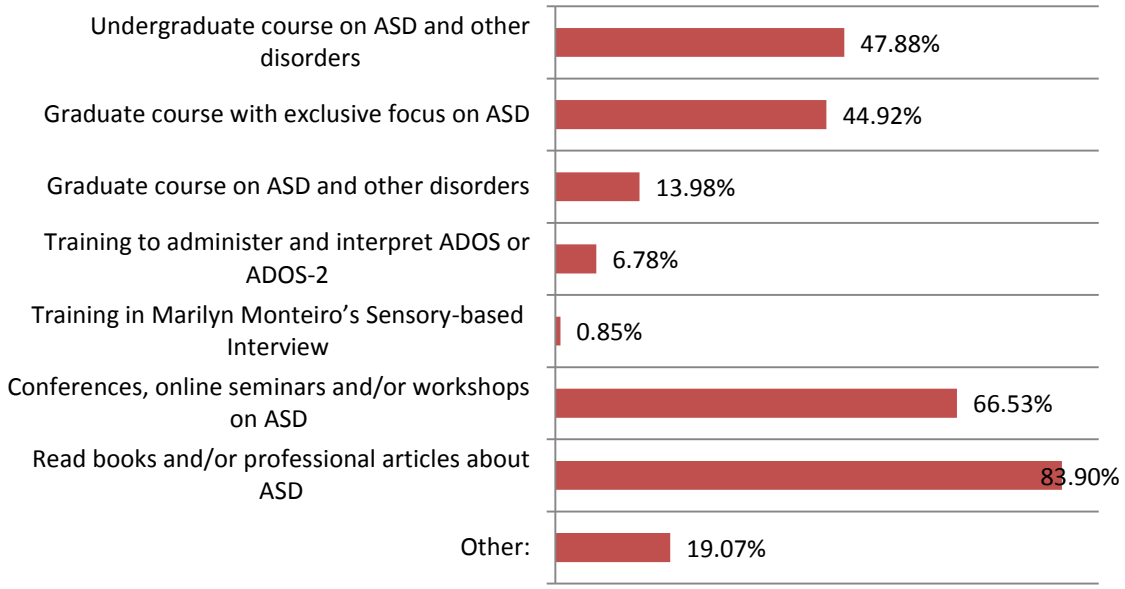


Figure 6. Answers to question 11 (Q11): What training have you had in diagnosing ASD?

Question twelve (Q12) tested the professional's understanding and knowledge by asking which characteristics are necessary to be able to identify a child as having ASD. Having the option of choosing more than one answer, 96.19% of respondents marked *qualitative impairment in social interaction;* 89.83% marked *qualitative impairment in communication;* 88.14% marked *restricted, repetitive pattern of behavior or interests;* 86.86% marked *little to no eye contact;* 74.58% marked *lack of ability to initiate/maintain shared attention;* 68.22% marked *echolalia;* 66.10% marked *onset during early childhood;* 56.36% *marked hand flapping*; and 50.85% marked *does not show affection*. Other answers included *sensory processing disorder; lack of symbolic play; low playfulness; use the other as an object; absence of sensibility to pain; apparent auditory sensitivity;* and *apparent lack of modesty even after the genital stage* (see Figure 7).

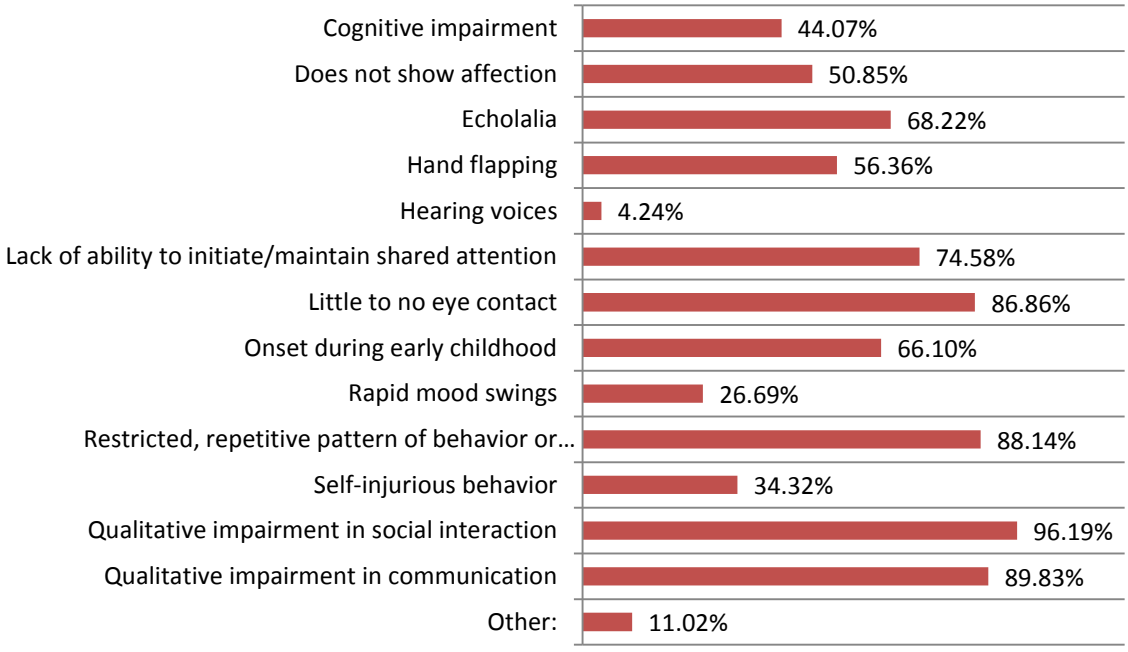


Figure 7. Answers to question 12 (Q12): Which of the following characteristics are necessary to be able to identify a child as having ASD?

Diagnostic Practices

The description of ASD diagnostic practices in Brazil is related to the answers to questions 6, 7, 8, 13. Question 13 (Q13) was about who referred the student/child to those professionals. Most of the respondents (61.86%) indicated *Teacher*, 57.63% *Parents*, 54.24% *Neurologist*, 35.59% *Pediatrician*, 34.32% *Psychologis*t, 33.90% *Psychiatrist*; 29.24% *Speech/Language Pathologist*, and 27.97% *Psychoeducator*, and *Other* (8.47%), which included *Occupational Therapist, Social Workers,* and *Friends of Autistic Association (AMA)* (see Figure 8).

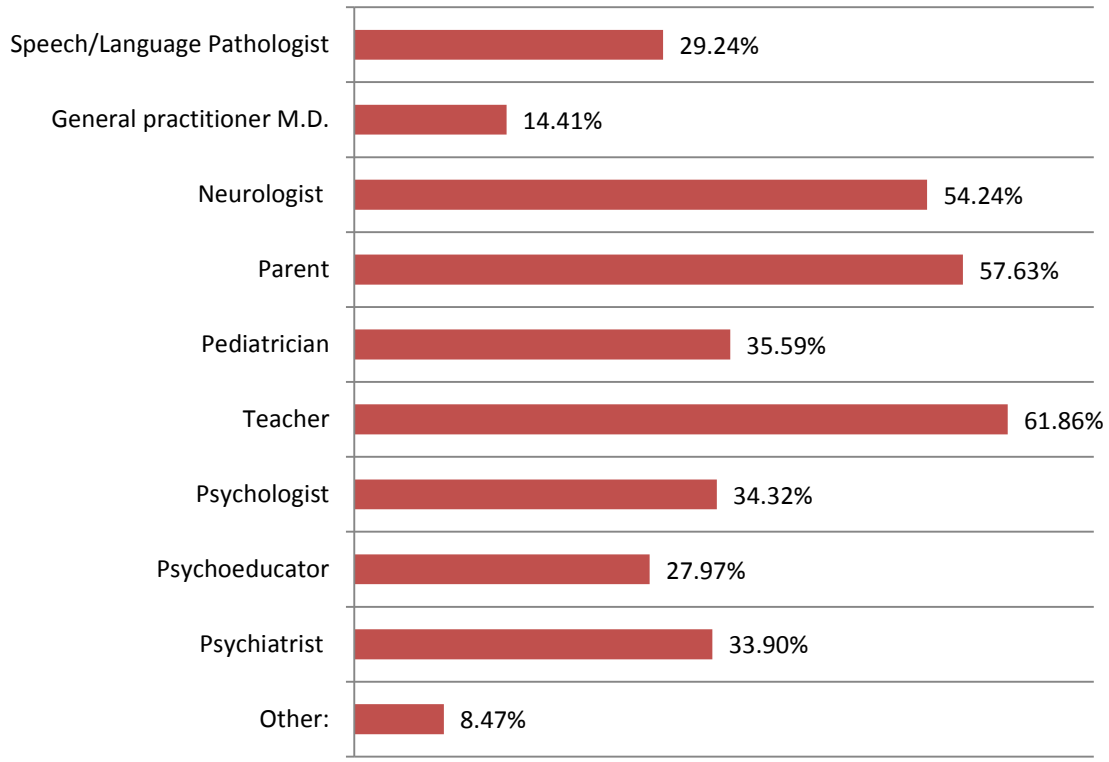


Figure 8. Answers to question 13 (Q13): Who referred the students/child to you?

Question six (Q6) asked *how long the professional spends per case when assessing for ASD*. This were the answers: 17 respondents indicated that they spend less

than one hour evaluating a case of ASD, 50 respondents between 1 and 2 hours, 48 respondents between 2 and 3 hours, 5 respondents between 3 and 4 hours, 27 respondents between 4 and 5 hours, 12 respondents between 5 and 6 hours, 14 respondents spend between 6 and 7 hours, 2 respondents between 7 and 8 hours, 1 respondent between 8 and 9 hours, 3 respondents between 9 and 10 hours, and 14 respondents between 10 and 11 hours evaluating an ASD case (see Figure 9).

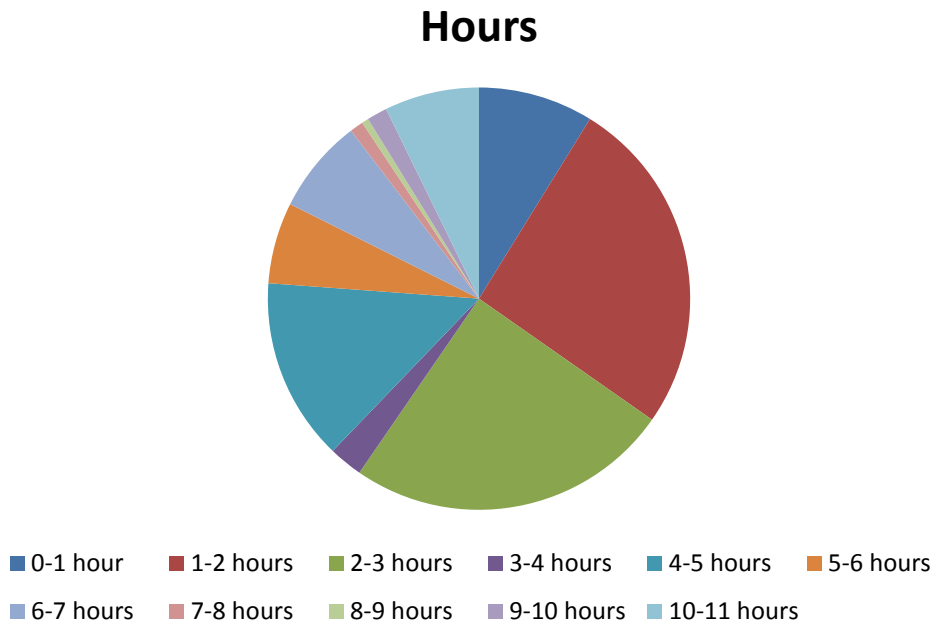


Figure 9. Answers to question 6 (Q16): On average, how many hours do you spend per case when assessing for ASD?

The next question (Q7) was about *what professionals constitute their diagnostic team when assessing for ASD*. Having the option to choose more than one answer, 69.92% reported *Neurologists*; 61.44% reported *Parents;* 51.27% reported *Regular education teacher*; 44.92% reported *Audiologist*, 44.49% reported a *Psychiatrist*, 35.17% reported *Educational Psychologist*; 33.05% reported *Psychoeducator*; 34.32% reported *Occupational Therapist*; 33.47% reported *Pediatrician;* 32.20% reported *Special*

Education Teacher; and 13.98% reported *other* such as *Psychologist* and *Relational Psychomotor* (see Figure 10).

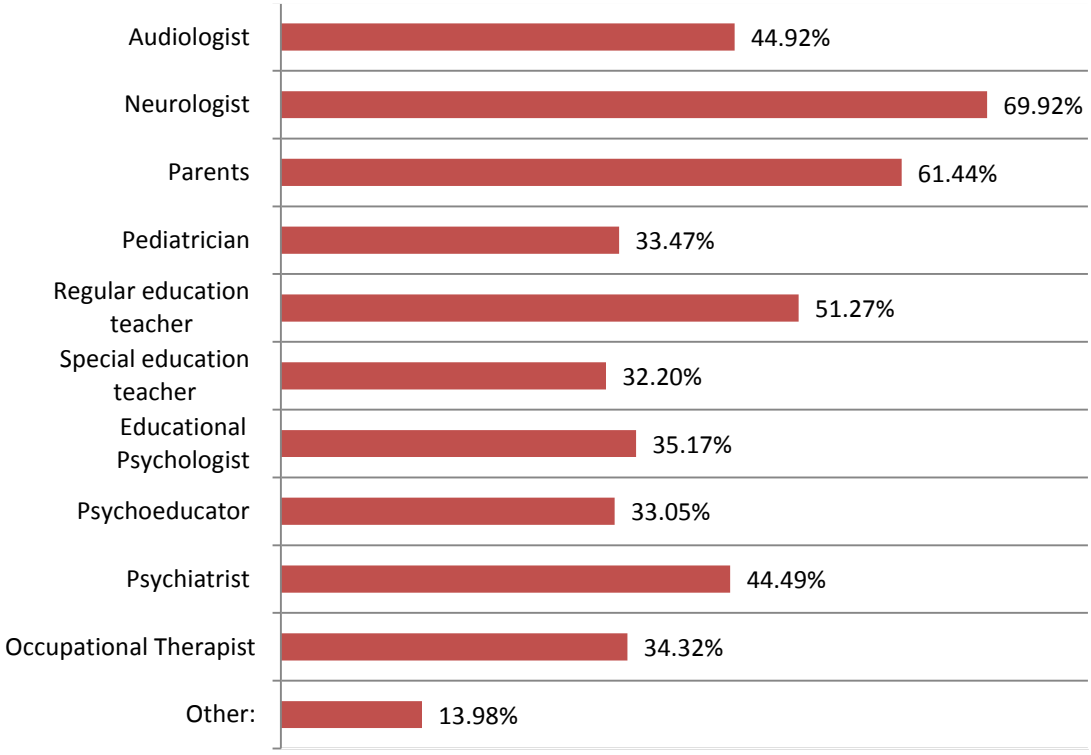
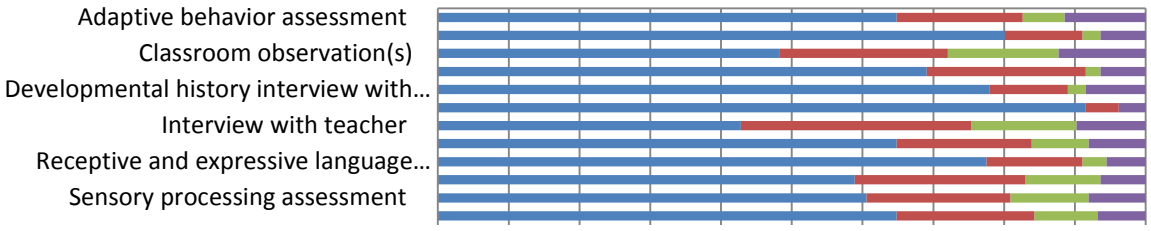


Figure 10. Answers to Question 7 (Q7): Which of the following constitute your diagnostic team when assessing for ASD?

Question 8 (Q8) was about *procedures that professionals use in evaluating for ASD*. These were the five answers with the highest percentages that respondents indicated they *almost always* use: *general interview with parent* (91.53%), *achievement assessment* (80.08%), *developmental history interview with parent specifically looking at ASD* (77.97%), *receptive and expressive language assessment* (77.54%), and *cognitive assessment* (69.07%). Other answers were marked by more than half of the respondents: *adaptive behavior assessment* (64.83%), *pragmatic language assessment* (64.83%), *direct/dynamic interaction with various team members* (64.83%), *sensory processing*

assessment (60.59%), and *record review* (58.90%). Among the twelve options, the procedures never used by professionals with the highest percentages were *classroom observations* (12.29%), *adaptive behavior assessment* (11.44%), and *interview with the teacher* (9.75%) (see Figure 11).



	Direct/dynamic interaction with various team members	Sensory processing assessment	Record review	Receptive and expressive language assessment	Pragmatic language assessment	Interview with teacher	General interview with parent	Developmental history interview with parent, specifically looki...	Cognitive assessment (Avg. 3.54)	Classroom observation(s)	Achievement assessment	Adaptive behavior assessment
Almost always	64.83%	60.59%	58.90%	77.54%	64.83%	42.80%	91.53%	77.97%	69.07%	48.31%	80.08%	64.83%
Sometimes	19.49%	20.34%	24.15%	13.56%	19.07%	32.63%	4.66%	11.02%	22.46%	23.73%	11.02%	17.80%
Rarely	8.90%	11.02%	10.59%	3.39%	8.05%	14.83%	0.00%	2.54%	2.12%	15.68%	2.54%	5.93%
Never	6.78%	8.05%	6.36%	5.51%	8.05%	9.75%	3.81%	8.47%	6.36%	12.29%	6.36%	11.44%

Figure 11. Answers to question 8 (Q8): How often do you (or your team members) utilize the following procedures or measures in your evaluation for ASD?

Diagnostic Instruments

Another research interest concerns the instruments the professionals use in Brazil. Question 9 (Q9) was about that. In this case large percentages indicated that many of the instruments were never used by those professionals. More than half of respondents

(55.56%) of respondents *never* used the *Autism Treatment Evaluation Checklist (ATEC).* A large percentage of respondents also never used *Global Assessment of Functioning (AGF)* (55.07%), *Wechsler Adult Intelligence Scale (WAIS-III)* (52.17%), *ABFW Pragmatics Test* (46.38%), *Vineland Adaptive Behavior Scales* (45.89%), *Language Development Assessment (ADL)* (43.96%), *Vocabulary Test for ABFW* (43.5%), *Modified Checklist for Autism in Toddlers (M-CHAT)* (42.51%), *Childrens Global Assessment Scale (C-GAS)* (41.55%), and *Autism Behavior Checklist (ABC)* (41.55%). The four instruments that scored highest in the *almost always* option were *Childhood Autism Rating Scale (CARS-2F)* (37.20%), *Vocabulary Test for ABFW* (25.12%), ABFW Pragmatics Test (24.64%), and *Wechsler Intelligence Scale for Children (WISC-III)* (24.15%). *Other* responses (29) included *Psychoeducational Profile Revised (PER-R), Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP), Denver Developmental Screening Test (DDST), Sensory Profile Test (Winnie Dunn*), *School Performance Test (TDE), Facial Recognition Test* (*Baron-Cohen), Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (see Figure 12).

Post-diagnosis

The last research question is related to question 10 (Q10), *Which interventions are recommended after diagnosis*. The top recommendations were *Psychological support to parents and/or caregivers* (77.54%), *Speech therapy* (76.69%), *Regular assessments* (69.5%), *Educational psychology service* (67.37%), *Occupational Therapy* (64.83%)*; Family support program* (59.75%), *Referral to another professional* (47.88%), and *Drug*

prescription (39.83%). Respondents also suggested others (19%) such as *Applied Behavior Analysis* (*ABA*),

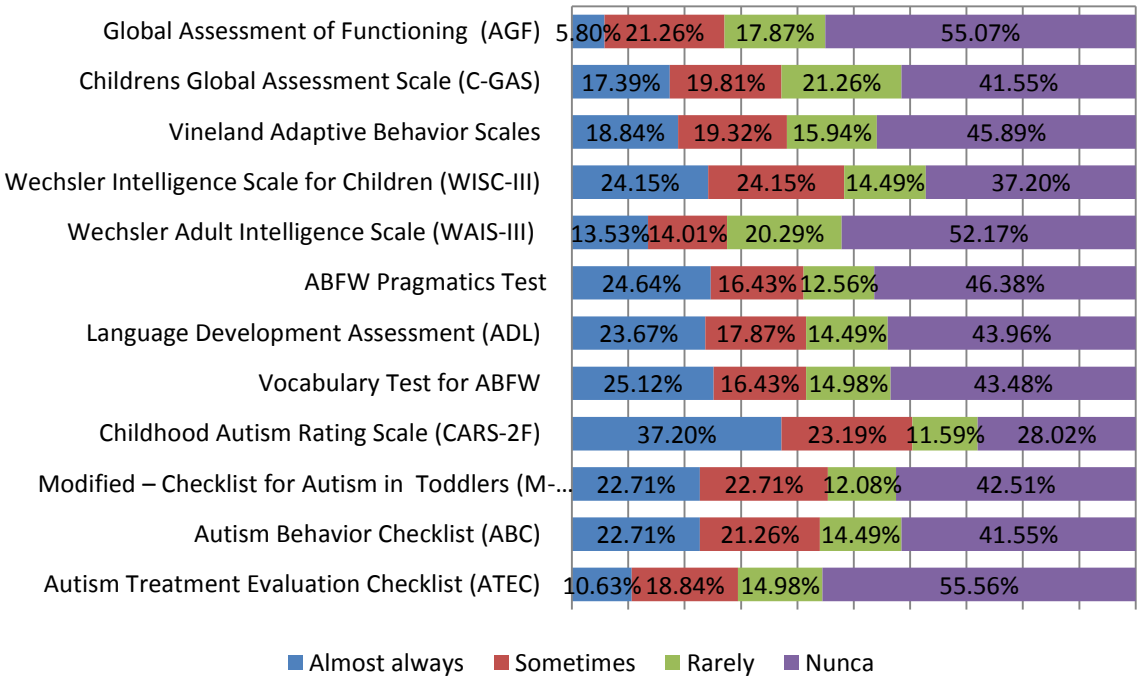


Figure 12. Answers to question 9 (Q9): How often do you (or your team members) utilize the following instruments or measures in your evaluation for ASD?

Multidisciplinary team; Psychiatric care; Physical Educator; Physiotherapist; School; Specialized Treatment Education (AEE); Picture Exchange Communication System (PECS); Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACHH); Relational Psychomotricity; Nutritionist; Child psychotherapy; Pediatric Neurology; Music Therapy; Special Education (see Figure 13).

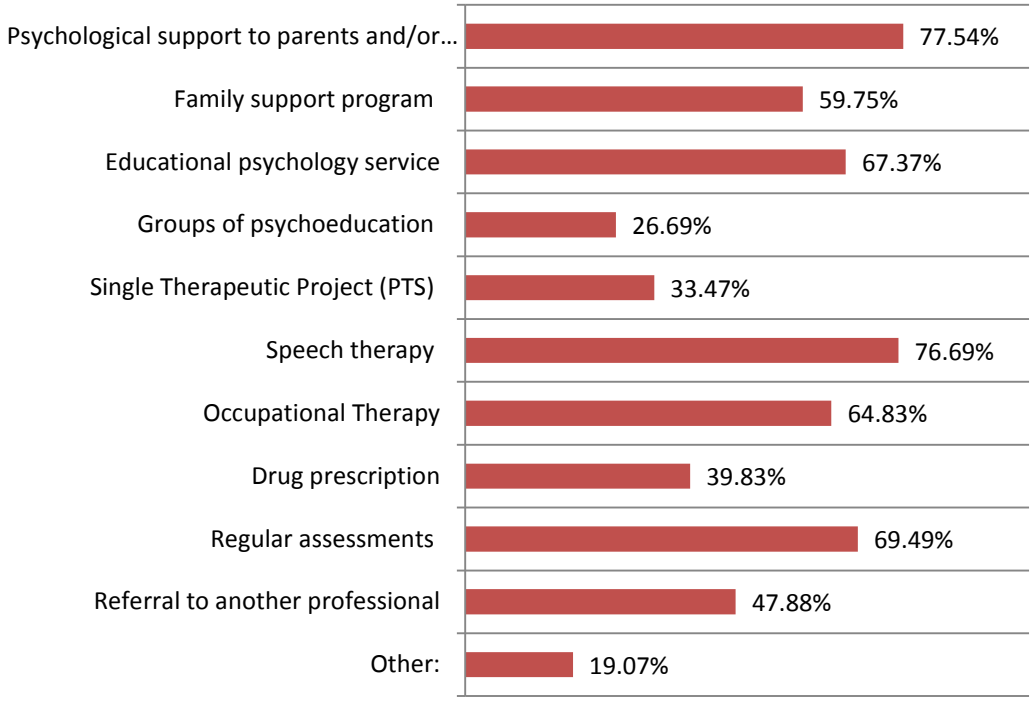


Figure 13. Answers to question 10 (Q10): Which interventions are recommended after diagnosis?

CHAPTER 5

DISCUSSION

Research Questions

Profile of Professionals

Important observations can be drawn from the responses related to the profile of professionals who diagnose ASD in Brazil (Q1, Q2, Q3, Q4, Q5). As mentioned in the previous chapter the total number of respondents was 236, being 11.86% men and 89.66% women. Although this research used a nonprobability sampling, this result is in line with the observation about the Brazilian reality. For example, the majority of Psychologists, one of the main professionals involved with diagnostic of Autism, is women (de Castro & Yamamoto, 1998, p. 155). As demonstrated in question 3 (Q3) most of the professionals who took part in the survey were Psychologists (42.80%), followed by Audiologists (25%), Psychiatrists (10.17%), and others (20.34%). This seems to reflect at least partially the reality of the diagnostic of ASD in Brazil. Unlike in the United States where Pediatricians and School Psychologists have the primary role, in Brazil Psychologists have taken that role.

More information about the profile of those professionals was gathered in question Q1a, such as the fact that most diagnostics are done with children between 5 and 10 years old (39.83%). This number is higher than the children between ages 1.5 and 5 and indicates a less-than-ideal scenario in which diagnostic is being done late, which is consistent with previous studies (Visani & Rabello, 2012, p. 293). Probably most children

receive their diagnostic after they start going to school. In the United States most cases are identified between the ages 1 and 3. The next part of question 1 (Q1b) showed that most professionals (77.54%) work more with male than (22.46%). This suggests a higher incidence of ASD among boys, which is consistent with other researches (Da Costa & Nunesmaia, 1998, p. 26) and is typical in other countries, such as the United States where "the ratio is one girl per 4 to 5 boys" (Paiva, 2010). Professionals were also surveyed about the socioeconomic status of their clients (Q1c). More than half of the professionals working with a majority of children from the middle class (58.90%). Poor children are the second largest group (31.78%). This seems to reflect the current social distribution in Brazil. According to the 2010 Census, 54% of the population is part of the middle class (*Censo 2010*, 2010). Geographic distribution (Q2) also seemed to reflect the actual scenario. São Paulo, Paraná, Rio de Janeiro, and Minas Gerais, most represented states in the survey, have some of the largest populations. According to Brazilian Institute of Geography and Statistics (IBGE), São Paulo is the most populous state in the country, with 43.6 million inhabitants, followed by Minas Gerais with 20.5 million residents, and Rio de Janeiro with 16.3 million people (*Censo 2010*, 2010).

Responses to questions four (Q4) and five (Q5) indicated that most professionals who diagnose children with ASD have little experience. Of the total participants (236), 164 (69.49%) respondents have 10 or fewer years of experience. Furthermore, only 42 (17.8%) had diagnosed at least 55 children throughout their career (38.98% have diagnosed fewer than 10 children), which supports the understanding of diagnostic being conducted by inexperienced professionals. This reality seems to be part of a cycle that includes low levels of awareness about ASD among the population, outdated curricula in

the universities, and difficult access to professionals. It also reflects the recent interest in researching ASD in Brazil.

In answering specifically the four main research questions, results of this research provide a description of the diagnostic practices of ASD in Brazil.

Knowledge and Training of Professionals

Answers about the training and knowledge of professionals who conduct diagnosis of ASD in Brazil (Q11 and Q12) seem to point to outdated university curricula. Training of those professionals in Brazil seem to come exclusively from books/articles and conferences/workshops. Less than half of the respondents indicated that they had an undergraduate or a graduate course that included ASD. The percentage of respondents that took a graduate-level class exclusively focused on ASD was approximately 14%. Very few academic programs in Brazil contemplate the reality of ASD.

Regarding the knowledge of those professionals, the survey showed a consensus around four major characteristics necessary to be able to identify a child as having ASD. More than 87% of respondents indicated impairment in social interaction, impairment in communication, restricted and repetitive pattern of behavior or interests, and little or no eye contact. Most professionals recognize the most common aspects of children with ASD.

Diagnostic Practices and Instruments

As far as diagnostic practices and tools (Q6, Q7, Q8, Q9, and Q13) the survey identified the following scenario:

Three groups of people refer children to professionals who conduct diagnostic for ASD more than half of the time (Q13): *Teacher,* 57.63% *Parents,* 54.24% *Neurologist,*

35.59%. Other professionals also refer abour 1/3 of the time: 35.59% *Pediatrician*, 34.32% *Psychologis*t, 33.90% *Psychiatrist*; 29.24% *Speech/Language Pathologist*, and 27.97% *Psychoeducator*.

About 2/3 of the time, professionals spend between 1-7 hours assessing for ASD (about 42% between 1-3 hours) (Q6). At least half of the time (Q7), this process includes Neurologists, Parents, and regular education teachers, but it will most likely include also Audiologists (45%), Psychiatrist (44.5%), Educational Psychologist (35.17%), and Psychoeducator (33.05%).

More than 3/4 of the time the diagnostic of ASD in Brazil will include these procedures (Q8): General interview with parents (91.5%), developmental history interview with parent (77.97%), achievement assessment (80.08%), receptive and expressive language assessment (77.54%). More than half of time, however, it will also include adaptive behavior assessment (64.83%), pragmatic language assessment (64.83%), *direct/dynamic interaction with various team members* (64.83%), *sensory processing assessment* (60.59%), and *record review* (58.90%).

More than half of the time professionals will use one or more of these nine instruments (Q9): *Childhood Autism Rating Scale (CARS-2F)* (71.98%), *Wechsler Intelligence Scale for Children (WISC-III)* (63.80%), *Autism Behavior Checklist (ABC)* (58.45%), *Children Global Assessment Scale (C-GAS)* (58.45%), *Modified-Checklist for Autism in Toddlers (M-CHAT)* (57.49%), *Vocabulary Test for ABFW* (56.52%), *Language Development Assessment (ADL)* (56.04%), *Vineland Adaptive Behavior Scales* (54.11%), and *ABFW Pragmatics Test* (53.62%).

Large percentages indicated that many of the instruments were never used by those professionals. More than half of respondents (55.56%) of respondents *never* used the *Autism Treatment Evaluation Checklist (ATEC).* A large percentage of respondents also never used *Global Assessment of Functioning (AGF)* (55.07%), *Wechsler Adult Intelligence Scale (WAIS-III)* (52.17%), *ABFW Pragmatics Test* (46.38%), *Vineland Adaptive Behavior Scales* (45.89%), *Language Development Assessment (ADL)* (43.96%), *Vocabulary Test for ABFW* (43.5%), *Modified Checklist for Autism in Toddlers (M-CHAT)* (42.51%), *Childrens Global Assessment Scale (C-GAS)* (41.55%), and *Autism Behavior Checklist (ABC)* (41.55%).

In summary, a multidisciplinary team usually does diagnosis of ASD in Brazil, in a relatively short period of time, and through a combination of various procedures and instruments. Further observations include the fact that Interview with teacher (42%) and Record Review (58.90%), as part of the diagnostic process, were expected to be almost a consensus and very low percentages for instruments ATEC and WAIS-III probably indicate that professionals are not familiar with these tools.

Among the instruments used in the United States the CARS was used more than any other rating scale in the evaluation process. Autism Diagnostic Observation Scale was used by only half of the school psychologists (Allen, Robin & Decker, 2008). Children's Autism Rating Scale is also the most used instrument in Brazil, while ADOS is not part of the recommended protocol for the state of Sao Paulo and it was not cited even by one respondent in the other option. M-CHAT, ABC, and ATEC appear in the protocol in English. A recent survey by AMA found confusion about instruments (including DSM-IV, CID 10, M-CHAT, and CHAT) and criteria for diagnostic in their

units. Almost half of the institutions indicated that they have their own method of diagnostic and 11.32% stated that they do not have any method. Among the instruments most mentioned were PEP-R (20.75%) and CARS (14.15%). Respondents also mentioned ABLLS, WISC, ABFW, AVDs, PRO-SELF, ABLA, CIF, and Vineland Scale (Mello et al., 2013, p. 52).

Post-diagnosis

The last research question related to interventions recommended after diagnosis (Q10). More than half of the time interventions will include *Psychological support to parents and/or caregivers* (77.54%), *Speech therapy* (76.69%), *Regular assessments* (69.5%), *Educational psychology service* (67.37%), *Occupational Therapy* (64.83%), and *Family support program* (59.75%). It is observable that high percentages of interventions seem to focus on the child's family instead of to him or her. Another observation is the relatively high percentage of drug prescription (39.83%), which suggests a classical orientation to ASD intervention. The somewhat contradictory observation in this case is the fact that referral to another professional is done in less than half of the cases. According to Visani & Rabello (2012), in Brazil, early treatment of autistic children takes so late not only because of failure to achieve early detection, but also because of the delay on the part of professionals and/or health institutions to give a formal diagnosis and carry out a referral to health professionals to deal with this serious psychopathology (Visani & Rabello, 2012, p. 293).

Implications for the Field

The results of this research suggest the need to invest in the training of professionals. Helpful measures include adding specific courses on ASD at both

undergraduate and graduate levels and organization of conferences for professional involved in diagnostic (pediatricians, psychiatrists), therapeutic (psychologists, speech therapists), and educational (teachers, educational psychologists) processes. Incentives for more publications on ASD should be part of these initiatives.

Another related suggestion is to develop specific criteria and common diagnostic protocol for professionals in Brazil. Ignorance about autism and how to deal with it have led many professionals involved in diagnostic and therapy to make mistakes. They do not know how to identify people with autism and what the best techniques are in those cases (Mello et al., 2013, p. 57).

Finally, providing access to inclusive education to people with autism would also provide them a more adequate opportunity for development. These initiatives would focus on individualized needs and different degrees of adaptation and support. Inclusive education does not substitute the need for specialized centers of autism. Those institutes can diffuse knowledge and help train on ASD (Mello et al., 2013, p. 59).

The implementation of these suggestions would still have little impact and take much longer if the government is not involved and does not support them by mobilizing the society, investing financial resources, and passing relevant legislation.

Limitations and Need for Further Study

It is evident, after this research, the need for demographic studies that provide reliable numbers about the incidence of ASD in Brazil. The low number of professionals who diagnose ASD in certain areas of the country not necessarily indicate fewer cases in those regions.

Based on the delimitations of this research, there is need for further study comparing diagnostic practices of ASD with the same process for other developmental disorders. The results would point to the general situation of special education in Brazil and to possible ways to improve awareness, training, and practices related to ASD.

It would also be important to develop studies to show the relation between diagnostics and interventions. It should consider practices and outcomes from both positive and negative views. Studies on children who are not diagnosed would also provide important information.

Finally, a delimitation of this research was the professionals in Brazil. Further study should be conducted comparing their practices with those of professionals in other countries especially in the United States. Since professionals in Brazil seem to rely on the same instruments for diagnosis of ASD, that study could reveal the degree of contextualization in their practices.

Silva and Mulick (2009) believe that it is necessary that models for the diagnostic practice, that have shown to be efficient and adequate in other countries, be included in the discussions among educators (p. 118). However, a step further seems to be necessary. Although the instruments of diagnosis translated and adapted to the Brazilian context seem appropriate to identify childhood autism, they are still based on the American society. Their use of an instrument "globally accepted" allows for more exchange of information between centers of research (Pereira, Riesgo, & Wagner, 2008, p. 488) but does not take into consideration the relevance of local cultural values.

This research may seem like a "drop in the ocean" in terms of research needs in Brazil. However, if professionals want to make a significant contribution to the treatment

of ASD, the first step seems to be a collection of drops in the “research bucket” that will survey the reality and point to new and improved ways as awareness brings development.

APPENDIX A

NIH CERTIFICATION

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Ana Dias** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 05/02/2013

Certification Number: 1170764

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Luana Greulich** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 03/05/2014

Certification Number: 1055054

APPENDIX B

NIH CERTIFICATION

Andrews University

Office of Research and Creative Scholarship
Institutional Review Board
(269) 471-6361 Fax: (269) 471-6246 E-mail: irb@andrews.edu
Andrews University, Berrien Springs, MI 49104-0355

APPLICATION FOR APPROVAL OF HUMAN SUBJECTS RESEARCH

Please complete this application as thoroughly as possible. Your application will be reviewed by a committee of Andrews University IRB, and if approved it will be for one year. Beyond the one year you will be required to submit a continuation request. It is the IRB's responsibility to assign the level of review: Exempt, Expedited or Full. It is your responsibility to accurately complete the form and provide the required documents. Should your application fall into the exempt status, you should expect a response from the IRB office within one (1) week; Expedited within two (2) weeks and a Full review 4-6 weeks.

Please complete the following application:

1. Research Project
a) Title: Cultural Factors and Diagnostic of Autism Spectrum Disorders in Brazil
Will the research be conducted on the AU campus? ___ Yes _**X**__ No

If no, please indicate the location(s) of the study and attach an institutional consent letter that references the researcher's study.

It will be an on-line study

b) What is the source of funding (please check all that apply)

__X_ Unfunded	
___ Internal Funding	Source:
___ External Funding	Sponsor/Source:
Grant title:	Award # / Charging String:

If you do not know the funding/grant information, please obtain it from your department

2. Principal Investigator (PI)

First Name: Ana **Last Name:** Dias **Telephone: (**269) 240-0756 **E-mail:** diasa@andrews.edu

__ Yes I am a student. If so, please provide information about your faculty advisor below.

First Name: Luana **Last Name:** Greulich **Telephone:** (269) 471-6332 **E-mail**: luana@andrews.edu

Advisor's signature:

Department: Graduate Psychology and Counseling **Program:** Educational Psychology

3. Co-investigators (Please list their names and contact information below)

First Name: **Last Name:** **Telephone:** **E-mail:**

First Name: **Last Name:** **Telephone:** **E-mail:**

First Name: **Last Name:** **Telephone:** **E-mail:**

First Name: **Last Name:** **Telephone:** **E-mail:**

4. Cooperating Institutions

Is this research being done in cooperation with any institutions, individuals or organizations not affiliated with AU?

___ Yes __X__ No If yes, please provide the names and contact information of authorized officials below.

Name of Organization: **Address:**

First Name: **Last Name:** **Telephone:** **E-mail:**

First Name: **Last Name:** **Telephone:** **E-mail**

Have you received IRB approval from another institution for this study? ___ Yes __ X__ No

If yes, please attach a copy of the IRB approval.

5. Participant Recruitment

Describe how participant recruitment will be performed. Include how and by whom potential participants are introduced to the study (please check all below that apply)

___ AU directory ___ Postings, Flyers ___ Radio, TV

_X__ E-mail solicitation. Indicate how the email addresses are obtained: personal contacts

_X__ Web-based solicitation. Specify sites: www.ama.org.br

___ Participant Pool. Specify what pool:

___ Other, please specify:

Please attach any recruiting materials you plan to use and the text of e-mail or web-based solicitations you will use.

6. Participant Compensation and Costs

Are participants to be compensated for the study? Yes ___ No _X__ If yes, what is the amount, type and source of funds?

Amount:	Source:	Type:

Will participants who are students be offered class credit? ___ Yes **_X__** No ___ NA

Are other inducements planned to recruit participants? ___ Yes **_X__** No If yes, please describe.

Are there any costs to participants? ___ Yes **_X__** No If yes, please explain.

7. Confidentiality and Data Security

Will personal identifiers be collected?	Will identifiers be translated to a code?
___ Yes **_X_** No	___Yes **_X_** No

Will recordings be made (audio, video)? ___Yes **_X_** No If yes, please describe.

Who will have access to data (survey, questionnaires, recordings, interview records, etc.)? Please list below.

The researcher and her advisors

8. Conflict of Interest

Do you (or any individual who is associated with or responsible for the design, the conduct of or the reporting of this research) have an economic or financial interest in, or act as an officer or director for, any outside entity whose interests could reasonably appear to be affected by this research project: ___ Yes **_X_** No

If yes, please provide detailed information to permit the IRB to determine if such involvement should be disclosed to potential research subjects.

9. Results

To whom will you present results (highlight all that apply)

_X__ Class **__X_** Conference **__X_** Published Article **___** Other If other, please specify:

10. Description of Research Subjects

If human subjects are involved, please highlight all that apply:

___ Minors (under 18 years) **___** Prison inmates **___** Mentally impaired **___** Physically disabled

___ Institutionalized residents **___** Anyone unable to make informed decisions about participation

___ Vulnerable or at-risk groups, e.g., poverty, pregnant women, substance abuse population

11. Risks

Are there any potential damage or adverse consequences to researcher, participants, or environment? These include physical, psychological, social, or spiritual risks whether as part of the protocol or a remote possibility.

Please highlight all that apply (Type of risk):

___ Physical harm **___** Psychological harm **___** Social harm **___** Spiritual harm

12. Content Sensitivity

Does your research address culturally or morally sensitive issues? **___** Yes **_X_** No If yes, please describe:

13. Please provide (type in or copy - paste or attach) the following documentation in the boxes below:

Protocol: See page 5

Survey instrument or interview protocol: Survey in English, see page 16; Survey in Portuguese, see page 23

Institutional approval letter (if off AU campus):

Consent form (for interviews and focus groups): Consent form in English, see page 14; Consent form in Portuguese, see page 22

Participants recruitment documents: N/A

Principal Investigator's Assurance Statement for Using Human Subjects in Research

__x__ I certify that the information provided in this IRB application is complete and accurate.

__x__ I understand that as Principal Investigator, I have ultimate responsibility for the conduct
of IRB approved studies, the ethical performance of protocols, the protection of the rights and welfare of human subjects, and strict adherence to the study's protocol and any stipulation imposed by Andrews University Institutional Review Board.

__x__ I will submit modifications and / or changes to the IRB as necessary prior to implementation.

__x__ I agree to comply with all Andrews University's policies and procedures, as well as with all applicable federal, state, and local laws, regarding the protection of human participants in research.

__x__ My advisor has reviewed and approved my proposal.

APPENDIX C

QUESTIONNAIRE

Autism Spectrum Disorders Assessment Survey

For purposes of this survey, Autism Spectrum Disorders (ASD) include Autism, PDD-NOS, and Asperger's Disorder as defined by the Diagnostic Statistical Manual, Fourth Edition (DSM-IV).

1. Please check the information on the population with whom you work **the most**:

   Choose one answer in each category

   a. Age:

   ( ) 6 months to 1 ½ year old

   ( ) 1 ½ to 5 years old

   ( ) 5 to 10 years old

   ( ) 10 to 15 years old

   ( ) 15 to 20 years old

   ( ) 20 to 25 years old

   ( ) above 25 years old

   b. Gender: ( ) Female ( ) Male

c. Socioeconomic status: ( ) poverty ( ) middle ( ) wealthy

2. State in which you are employed: _____

3. Which is your professional practice?
   ( ) Audiologist
   ( ) Neurologist
   ( ) Pediatrician
   ( ) Psychologist
   ( ) Psychiatrist
   ( ) Other: _____

4. Years of professional experience in this area: _____

5. Approximately how many children have you assessed for possible ASD (over your full career)? _____

6. On average, how many hours do you spend per case when assessing for ASD? _____

7. Which of the following constitute your diagnostic team when assessing for ASD?
   Check any that apply

   ( ) Autism Consultant
   ( ) General Education Teacher
   ( ) Parent
   ( ) School Psychologist
   ( ) Special Education Teacher
   ( ) Speech/Language Pathologist
   ( ) Occupational Therapist

( ) Other: _____

8. How often do you (or your team members) utilize the following **PROCEDURES** in your evaluation for ASD:

	Never	**Rarely**	**Sometimes**	**Almost Always**
Adaptive behavior assessment				
Achievement assessment				
Classroom observation(s)				
Cognitive assessment				
Developmental history interview with parent, specifically looking at ASD (e.g. ADI-R)				

General interview with parent				
Interview with teacher				
Pragmatic language assessment				
Receptive and expressive language assessment				
Record review				
Sensory processing assessment				
Direct/dynamic interaction with various team members				

9. How often do you (or your team members) utilize the following **INSTRUMENTS** or measures in your <u>evaluation</u> for ASD:

	Never	**Rarely**	**Sometimes**	**Almost Always**
Global Assessment of Functioning (AGF)				
Childrens Global Assessment Scale (C-GAS)				
Vineland Adaptive Behavior Scales				
Wechsler Intelligence Scale for Children (WISC-III)				
Wechsler Adult Intelligence Scale (WAIS-III)				
ABFW Pragmatics Test				
Language Development Assessment (ADL)				

Vocabulary Test for ABFW				
Childhood Autism Rating Scale (CARS-2F)				
Modified Checklist for Autism in Toddlers (M-CHAT)				
Autism Behavior Checklist (ABC)				
Autism Treatment Evaluation Checklist (ATEC)				
Social Communication Questionnaire(SCQ)				
Other:				

10. Which interventions are recommended after diagnosis? ***Check any that apply***

( ) Single Therapeutic Project (PTS)

( ) Speech therapy

( ) Occupational Therapy

( ) Psychological support to parents and/or caregivers

( ) Groups of psychoeducation

( ) Family support program

( ) Drug prescription

( ) Regular assessments

( ) Referral to another professional**:** _____

( ) Other: _____

11. What training have you had in diagnosing ASD?

Check any that apply

( ) Undergraduate course on ASD and other disorders

( ) Graduate course with exclusive focus on ASD

( ) Graduate course on ASD and other disorders

( ) Training to administer and interpret ADOS or ADOS-2

( ) Training in Marilyn Monteiro's Sensory-based Interview

( ) Conferences, online seminars and/or workshops on ASD

( ) Read books and/or professional articles about ASD

12. Which of the following characteristics are **necessary** to be able to identify a child as having ASD?

Check any that apply

( ) Cognitive impairment

( ) Does not show affection

( ) Echolalia

( ) Hand flapping

( ) Hearing voices

( ) Lack of ability to initiate/maintain shared attention

( ) Little to no eye contact

( ) Onset during early childhood

( ) Rapid mood swings

( ) Restricted, repetitive pattern of behavior or interests

( ) Self-injurious behavior

( ) Qualitative impairment in social interaction

( ) Qualitative impairment in communication

13. Who referred the student/child to you? ***Check any that apply***

( ) Speech/Language Pathologist

( ) General practitioner M.D.

( ) Neurologist

( ) Parent

( ) Pediatrician

( ) Teacher

( ) Psychologist

( ) Psychiatrist

( ) Other: _____

APPENDIX D

IRB APROVAL

June 20, 2014
Ana Dias
Tel: (269) 240-0756
Email: diasa@andrews.edu

RE: APPLICATION FOR APPROVAL OF RESEARCH INVOLVING HUMAN SUBJECTS
IRB Protocol #:14-069 **Application Type**: Original **Dept.:** Graduate Pschology & Counseling
Review Category: Exempt **Action Taken:** Approved **Advisor:** Luana Greulich
Title: Cultural Factors and Diagnostic Practices of Autism Spectrum Disorders in Brazil. Your IRB application for approval of research involving human subjects entitled:

"Cultural Factors and Diagnostic Practices of Autism Spectrum Disorders in Brazil" IRB protocol # 14-069 has been evaluated and determined exempt from IRB review. You may now proceed with your research.

Please note that any future changes made to the study design and/or informed consent form require prior approval from the IRB before such changes can be implemented. Incase you need to make changes please use the attached report form.

While there appears to be no more than minimum risks with your study, should an incidence occur that results in a research-related adverse reaction and/or physical injury,

this must be reported immediately in writing to the IRB. Any research-related physical injury must also be reported immediately to the University Physician, Dr. Reichert, by calling (269) 473-2222.

We ask that you reference the protocol number in any future correspondence regarding this study for easy retrieval of information.

Best wishes in your research.

Sincerely,

Mordekai Ongo

Research Integrity & Compliance Officer

References

Allen, R. A., Robins, D. L., & Decker, S. L. (2008). Autism Spectrum Disorders: Neurobiology and current assessment practices. *Psychology in the Schools*, 45(10), 905-917.

American Psychiatric Association. (1980). *DSM-III. Diagnostic and statistical manual of mental disorders* (3th ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (1987). *DSM-III-R. Diagnostic and statistical manual of mental disorders* (3th ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2003). *Diagnostic and statistical manual of mental disorders, fourth edition: DSM-IV-TR.* Washington, DC: American Psychiatric Association.

American Psychiatric Association & DSM Task Force. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5.* Retreived from http://dsm.psychiatryonline.org/book.aspx?bookid=556

Bailey, A., Phillips, W., & Rutter, M. (1996). Autism: Towards an integration of clinical, genetic, neuropsychological, and neurobiological perspectives. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, *37*(1), 89-126.

Barbaresi, W., Colligan, R., Weaver, A., & Katusic, S. (2009). The incidence of clinically diagnosed versus research-identified Autism in Olmsted County, Minnesota, 1976–1997: Results from a retrospective, population-based study. *Journal of Autism & Developmental Disorders, 39*(3), 464-470.

Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can Autism be detected at 18 months? The needle, the haystack, and the CHAT. *The British Journal of Psychiatry*, *161*(6), 839-843.

Becker, M. M. (2009). *Tradução e Validação da Entrevista Autism Diagnostic Interview-Revised (ADI-R) para Diagnóstico de Autismo no Brasil.* Master Thesis, Universidade Federal do Rio Grande do Sul, Porto Alegre, RS.

Bragin, J. M. B. (2011). Antecedentes da Educação de Autistas no Brasil: Teorias políticas e suas influências nas práticas pedagógicas em centros de atendimento especializado. *Fermentario, 5*.

Brasil tem 40,3 milhões de estudantes na rede pública, diz Censo Escolar. (2013). Retrieved from http://g1.globo.com/educacao/noticia/2013/09/brasil-tem-403-milhoes-de-estudantes-na-rede-publica-diz-censo-escolar.html

Câmara Municipal do Rio de Janeiro. (2014). Capacitação para o Diagnóstico do Autismo em Rede Municipal. *Saúde/Tramento Multidiciplinar.* Retrieved from http://www.brasilnoticia.com.br/saude/capacitacao-para-o-diagnostico-do-autismo-em-rede-municipal/26975

Certo, A. L. & Bervian, P. A. (1996). *Metodologia científica*. São Paulo, BR: Makron Books.

Charman, T. & Baird, G. (2002). Practitioner review: Diagnosis of Autism Spectrum Disorder in 2- and 3-year-old children. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 43*(3), 289.

Costa, U. (2013). *Autismo no Brasil, Um Grande Desafio!* Rio de Janeiro, RJ: Wak.

Da Costa, M. I. F. & Nunesmaia, H. D. S. (1998). Diagnóstico genético e clínico do Autismo infantil. *Arq Neuropsiquiatr, 56*(1), 24-31.

de Castro, A. E. F. & Yamamoto, O. H. (1998). A psicologia como profissão feminina: Apontamentos para estudo. *Estudos de Psicologia, 3*(1), 147-158.

Felicio, V. C. (2007). O autismo e o professor: Um saber que pode ajudar. *Trabalho de conclusão de curso de Pedagogia, Universidade Estadual Paulista–UNESP, Bauru*.

Gadia, C. A., Tuchman, R., & Rotta, N. T. (2004). Autismo e doenças invasivas de desenvolvimento. *Jornal de Pediatria, 80*, 83-94.

Gardiner, H. W. & Kosmitzki, C. (2008). *Lives across cultures: Cross-cultural human development* (4th ed.). Boston, MA: Pearson Allyn and Bacon.

Giardinetto, A. R. d. S. B. (2005). Comparando a interação social de crianças autistas: As contribuições do programa TEACCH e do Currículo Funcional Natural. *Universidade Federal de São Carlos, UFSCAR.*

Grinker, R. R. (2007). *Unstrange minds: Remapping the world of Autism*. New York, NY: Basic Books.

Instituto Brasileiro de Geografia e Estatistica. (2010). *Censo 2010.* Retrieved from http://censo2010.ibge.gov.br/.

Jorge, L. M. D. (2003). *Instruments of evaluation of autistic children: Literature review.* Master Thesis, PUC-Campinas, Campinas, SP. Retrieved from http://tede.bibliotecadigital.puc-campinas.edu.br:8080/jspui/handle/tede/278

Junior, P. & Ribeiro, S. (2010). *Pesquisa do CDC revela número alto de prevalência de Autismo nos EUA em crianças de oito anos, além de grande aumento em relação a pesquisa anterio*r. Revista Autismo: Informação gerando ação.

Kang-Yi, C., Grinker, R., & Mandell, D. (2013). Korean Culture and Autism Spectrum Disorders. *Journal of Autism & Developmental Disorders*, *43*(3), 503-520.

Kanner, L. (1943). *Autistic disturbances of affective contact*. Publisher not identified.

Kwee, C. S., Sampaio, T. M. M., & Atherino, C. C. T. (2009). Autismo: Uma avaliação transdisciplinar baseada no programa TEACCH. *Revista CEFAC, 11,* 217-226.

Laznik, M. (2000). Poderia a teoria lacaniana da pulsão fazer avançar a pesquisa sobre o Autismo. *Psicanálise e clínica de bebês*, *4*(3), 76-90.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., ... & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with Autism: Data from the National Survey of Children's Health. [Research Support, Non-U.S. Gov't]. *J Dev Behav Pediatr, 29*(3), 152-160.

Ludke, J. P. R. (2011). *Autismo e inclusão na educação infantil: Um estudo sobre as crenças dos educadores. Trabalho de conclusão de especialização. Instituto de Psicologia - UFRGS*. Retrieved from http://hdl.handle.net/10183/32836

Mandell, D. S., Wiggins, L. D., Yeargin-Allsopp, M., Carpenter, L. A., Daniels, J., . . . Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with Autism Spectrum Disorders. *American Journal of Public Health, 99*(3), 493-498.

Mash, E. J. & Barkley, R. A. (2006). *Assessment of childhood disorders* (3th ed.). New York, NY: Guilford Press.

McMillan, J. H. & Schumacher, S. (2010). *Research in education: Evidence-based inquiry* (7th ed.). Boston, MA: Pearson.

Matson L. J. (2008). *Clinical Assessment and Intervention for Autism Spectum Disorders*. Burlington, MA: Elsevier.

Mello, A. M. (2005). *Autismo: Guia prático*. São Paulo, SP: AMA - Associação de Amigos do Autista, Brasília.

Mello, A. M., Ho, H., Dias, I., & Andrade, M. (2013). *Retratos do Autismo no Brasil* (1ª ed.). São Paulo, SP: AMA - Associação de Amigos do Autista.

Mendes, E. G. (2006). A radicalização do debate sobre inclusão escolar no Brasil. *Revista Brasileira de Educação, 11*(33), 387-405.

Montagner, J., Santiago, È., & Souza, M. G. (2007). Dificuldades de interação dos profissionais com as crianças autistas de uma instituição educacional de Autismo. *Arq. ciênc. saúde, 14*(3), 169-174.

Paiva, J. (2010). Impressive number: One per 110 children has Autism. *Revista Autimo,* 73.

Paula, C. S., Ribeiro, S. H., Fombonne, E., & Mercadante, M. T. (2011). Brief Report: Prevalence of Pervasive Developmental Disorder in Brazil: A Pilot Study. *Journal of Autism and Developmental Disorders, 41*(12), 1738-1742.

Pereira, A., Riesgo, R. S., & Wagner, M. B. (2008). *Autismo infantil: Tradução e validação da Childhood Autism Rating Scale para uso no Brasil. Jornal de Pediatria, 1678-4782.* Retrieved from http://dx.doi.org/10.1590/S0021-75572008000700004.

Possi, K. C. & de Holanda, M. V. (2011). O Impacto do Diagnóstico de Autismo nos Pais e a Importância da Incerção Precoce no Tratamento de Criança Autista. *Psychiatry on line Brasil, 16*(1).

Rosenberg, R. E., Daniels, A. M., Law, J. K., Law, P. A., & Kaufmann, W. E. (2009). Trends in Autism Spectrum Disorder diagnoses: 1994-2007. *Journal of autism and developmental disorders, 39*(8), 1099-1111.

Sato, F. P., Paula, C. S., Lowenthal, R., Nakano, E. Y., Brunoni, D., ... & Mercadante, M. T. (2009). Instrument to screen cases of pervasive developmental disorder: A preliminary indication of validity. *Rev. Bras. Psiquiatr. Revista Brasileira de Psiquiatria, 31*(1), 30-33.

Schwartzman, J. S. (2003). *Autismo infantil*. São Paulo, BR: Memnon.

Silva, M. & Mulick, J. A. (2009). Diagnosing autistic disorder: Fundamental aspects and practical considerations. *Psicologia: ciência e profissão, 29*(1), 116-131.

Smith, D. (2004). *Introduction to special education: Teaching in an age of opportunity* (5th ed.). Boston, MA: Pearson.

Smith, D. & Tyler, N. (2010). *Introduction to special education: Making a difference* (7th ed.). Upper Saddle River, NJ: Merrill.

Social, A. d. C. (2013). *Tratamento do Autismo entra na pauta da Comissão de Saúde.* Retrieved from http://www.alba.ba.gov.br/noticias/Noticia.php?id=15874

Tamanaha, A. C., Martins, A. C. P., Maia, A. K., Paula, C. S., Bordini, D., . . . Ribeiro, T. C. (2013). *Protocolo do Estado de São Paulo de Diagnóstico Tratamento e Encaminhamento de Pacientes com Transtorno do Espectro Autista (TEA)*. São Paulo, SP: SEDPcD Retrieved from http://www.pessoacomdeficiencia.sp.gov.br.

Thomas, A. & Grimes, J. (2002). *Best Practices in School Psychology IV* (4th ed. Vol. 2 Volume Set). Bethesda, MD: National Association of School Psychologists.

Thomas, A. & Grimes, J. (2008). *Best Practices in School Psychology V* (5th ed.). Bethesda, MD: National Association of School Psychologists.

Tibyriça, F. R. (2013). *Cartilha Direitos das Pessoas com Autismo*. Rio Grande do Sul, BR: Associação Mantenedora Pandorga, Rede Gaúcha Pró-Autismo.

U. S. Department of Education. (2004). *Building the Legacy: IDEA 2004*. Retrieved from http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CA%2C300%252E8%2Cc%2C1%2Ci%2C.

Visani, P. & Rabello, S. (2012). Considerações sobre o diagnóstico precoce na clínica do autismo e das psicoses infantis. *Revista Latinoamericana de Psicopatologia Fundamental, 15*(2), 293-308.

Wilkinson, L. A. (2010). *A Best Practice Guide to Assessment and Intervention for Autism and Asperger Syndrome in Schools* (1st ed.). Philadelphia, PA: Jessica Kingsley.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva, CH: World Health Organization.