Section I: Background Information

Terminology and Perspective
People from Puerto Rico are referred as *puertorriqueño* (or *puertorriqueña* for feminine gender classification in Spanish Language) o *puertorricense*. Other terminologies are also used, including the terms *boricua*, *borinqueño* and *borincano* (or *borinqueña* and *borincana*, respectively), stemming from the name that our native Taíno people had originally given the Island: *Borikén*. Our preferred terminology is *puertorriqueños* or, in English, Puerto Ricans, which we will use throughout this chapter.

We will present the following content from the perspective of three Puerto Rican neuropsychologists. All of us completed doctoral degrees in Puerto Rico, and two of us circulated to the United States for the completion of post-doctoral fellowships in Neuropsychology. We are all bilingual (Spanish/English) and currently work in both academic settings and private practice in Puerto Rico.

Geography
Puerto Rico is the smallest of the Greater Antilles in the Caribbean, located between Hispaniola and the Virgin Islands. Puerto Rico itself is a small archipelago surrounded to the north by the Atlantic Ocean and to the south by the Caribbean Sea. Its geographical extension is approximately 100 × 35 miles.

Puerto Rico has a warm tropical climate throughout the year that provides a very colorful natural landscape. The shores of Puerto Rico have beautiful beaches and the center of the Island is mountainous with several rain forests and diverse vegetation. This climate is considered decisive in the culture, in the economy, and in the formation of the cheerful, communicative, and spontaneous characteristics of the people.¹

However, its tropical climate and geographical location expose the Island to the passage of frequent storms and hurricanes. In addition, Puerto Rico is surrounded by several geological faults that have been recently active on the southwestern part of the Island.

History
Puerto Rico was identified in 1493 by Christopher Columbus and colonized by Spain by 1508. At that time, the Island was populated by native Taíno culture, described as a tribal society. That culture rapidly diminished due to diseases and forced labor to retrieve gold for the colonizers.²

DOI: 10.4324/9781003051862-69
However, cultural and racial traits from Taínos are still present throughout our vocabulary, art, folklore, and food.

From the 17th century, the Spanish introduced enslaved and displaced individuals from Africa to work in agriculture, considerably increasing the Afro-descendant population on the Island. This practice was abolished in 1873. However, the African influence has been a significant determining factor in our national identity. This heritage extends to our vocabulary, food, arts, music, religion, and physical features. Overall, we consider ourselves mainly a racial mix of the native Taínos, Africans, and Europeans originating mostly from Spain.

The uniquely Puerto Rican identity can be traced to the 19th century, when national awareness grew out of independent and autonomous movements from the Spanish metropolis. Puerto Rico was able to obtain regional autonomy from Spain only months before the North American invasion in 1898, during the Spanish–American war. After the war, Puerto Rico was ceded to the United States along with Cuba and other Pacific Islands. Puerto Rico is still an unincorporated territorial possession and is considered the world’s oldest colony.

The change of sovereignty implied an attempt of transculturation, substituting the Hispanic culture for the Anglo-Saxon one. Military bases were quickly installed, and the US currency was established. Since 1917, Puerto Ricans have been citizens of the United States, allowing them to enlist in its armed forces and travel freely to and from the United States. Since 1952, Puerto Rico established a relationship with the United States known as the Commonwealth of Puerto Rico. This allowed for a government with greater “autonomy.” This political formula quickly transformed Puerto Rico from an agricultural to an industrial economy, producing a cultural breakdown with problems reconfiguring a new set of values. Because it is still a colony, Puerto Ricans do not control their borders. Federal laws overcome local laws. Economy is also controlled by the United States, along with their cabotage laws. Puerto Ricans living in Puerto Rico are not allowed to vote in US elections, despite being US citizens.

Today’s Puerto Rican culture integrates much of the American Way of Life, but without abandoning the Hispanic heritage. The Spanish of Puerto Rico is full of Anglicisms and many of our behaviors (eating habits, business organization, and residential developments) emulate the American middle class. Likewise, our institutions are a mixture of Anglo-Saxon and Hispanic traditions. For example, the educational system follows the North American culture, but our justice system maintains both civil law as well as common law. Also, Puerto Rico also has established communities of North American, Latin American, Caribbean, and even Asian cultures.

**People**

Puerto Rico is known as the Island of Enchantment for the beauty of its landscapes and for the hospitality of its people. Puerto Ricans are distinguished by their optimistic attitude, their good sense of humor, and a great sense of solidarity. For Puerto Ricans, family is the most important value. This caring attitude, along with the strong family support system, is present in many families that we see.

The sense of group and familiarity is also seen in our teamwork. We all met within the Clinical Psychology doctoral program at the same university. We are all currently colleagues, but we have in the past worked in a supervisor-trainee and/or professor-student relationship. The case that we will present was initially referred by a family friend, and throughout the years, the family kept frequent communication with us.

**Migration or “Circulation”**

Puerto Rico is one of the countries with the highest migration rates in the world. Currently, 5.5 million Puerto Ricans live in the United States, which represents 61% of our population.
Large migratory waves to US agricultural and industrial centers started in the last century due to government policies and the convenience of having American citizenship. Most recently, new migratory waves are seen from families looking for better educational, health, and employment opportunities, particularly after recent natural disasters. This has resulted in a population decline of −3.5% on the Island. These Puerto Ricans in the United States maintain their culture, as well as social and family ties. That is why, instead of migration, many families experience a “circulation” between Puerto Rico and the United States.

Language
As a Hispanic country, 95% of Puerto Rican communities use Spanish in daily activities. Our Spanish has a rich and diverse vocabulary from Taíno, African, and English dialect influences. Public school systems include English as part of the regular curriculum for all grades, which means all Puerto Ricans obtain some level of English instruction. Many private schools provide bilingual education. There are some people that perceive that the English language is better taught in private schools. In technical and industrial contexts, and in certain academic fields, English can be frequently used. Universities maintain Spanish as the main language but often require some courses in English. In specialty courses, the textbooks and other references are often in English, even when the classes are taught in Spanish. This is also our case as neuropsychologists: many of our training, continuing education, and the references we use are from scientific literature are written in English. Puerto Ricans are also very exposed to English through television, radio, the press, and most recently, through social media and the internet. However, it is estimated that less than 20 percent of the Island’s population speaks English at an advanced level.

Education
The education system of Puerto Rico follows the North American model from preschool to university level. By constitutional law, the Puerto Rico government currently provides education to 424,000 children in 1,464 public schools. Of these, around 29% participate in the Special Education Program (SEP), according to the Individuals with Disabilities Education Improvement Act. This is a US law that guarantees from the government free and appropriate public education to all students with disabilities, as defined in different categories of mental, health, or physical impairments. The private educational system in Puerto Rico serves 149,000 students in 882 schools. However, special education services are not often provided within this system. When it is offered, the cost and expenses are high, exceeding the mean annual income of the typical Puerto Rican family.

Despite the legal status, the government of Puerto Rico has financial limitations, even political and administrative barriers, to provide all the individualized services that children need with their special education and in their transition from adolescence to adulthood. The process of requesting services is often slow and difficult, sometimes requiring going through legal channels. This often triggers migration to the United States. Recent natural disasters and the COVID-19 pandemic have worsened these difficulties.

Communication
Working with children means that the clinical approach must be family-oriented. Initial communication tends to be with the child’s caregiver, who is usually the mother. Although in our culture the father is considered the head of the traditional family, it is the mother who often assumes the leadership in childcare and the one who often provides more detailed information about the child’s development and the family system.
Age and professional levels tend to be respected, although it partially depends on educational and socio-economic factors. Regardless of socio-economic backgrounds, Puerto Ricans tend to be very respectful toward figures of “authority.” With time, that relationship might be perceived as a relationship of trust, and therefore, familiarity. It is important to keep a healthy balance between rapport and professional boundaries with families.

Shaking hands is often the preferred method of greetings, at the beginning and at the end of each session, particularly from and between men, but often as part of a professional relationship in any gender. When there is more trust and feelings of familiarity, a kiss on the cheek can be received from, and between, women. Communicative nonverbal gestures tend to be frequent.

Assertiveness can be a challenge sometimes, either from or to families. Some families are not ready to receive direct information of test results or diagnosis without first talking positively and establishing strong rapport. Empathy is required to gain trust. Empowerment is often needed.

**Literacy**

Puerto Rico is one of the most literate regions in America, with a literacy rate of 92%. This achievement is due to a large investment in education by the federal government. The Puerto Rican labor force has an average education of 12.6 years of study. About 2.5% reached advanced studies, including a doctorate. As for Puerto Rican migrants in the United States, they are the second group among Hispanics with the highest education. It is estimated that 19% have at least a bachelor’s degree. Some of the reasons for the remaining 8% on the Island being illiterate include poverty, gender violence, and immigration. Government literacy programs are available to those adults identified when seeking employment so that they can compete in the job market.

**Socio-Economic Status**

Over the past two decades Puerto Rico has experienced an economic contraction that has affected all government, private and personal sectors, including health and education services. This has been exacerbated by recent natural disasters: a major hurricane that devastated the Island causing thousands of deaths and the temporary collapse of the communication systems, electrical grid, and water supply and earthquakes on the southwestern part of the Island that destroyed properties and commercial activities. The COVID-19 pandemic has also been causing a significant stagnation in the economy. In 2018, the average annual salary of a working-class Puerto Rican family was $24,563. There are estimations that 36 of the 78 municipalities, or towns of Puerto Rico, have more than 50% of their population under poverty levels. These locations also report the lowest educational levels and limited availability of services. US government welfare is usually available for those below the poverty level.

As mentioned before, the Government of Puerto Rico has policies and resources aimed at providing services and supports for children. Although all families can access these services regardless of their social status, most of the working-class families in Puerto Rico require those services to assist in meeting their child’s needs. However, because it can be a slow and difficult process, parents with economic resources often pay for private, complementary services. This is a huge challenge, and to some point a disadvantage, because we all know that optimal outcomes of children with disabilities will be determined by early accessibility to health services, educational opportunities, and evidence-based interventions. Again, for many families, those opportunities are found by migrating to the United States, particularly if they have family ties in the mainland.
Values and Customs

We agree with a recent study\textsuperscript{13} that found that the most valuable thing for Puerto Ricans is the family (94%), followed by work (70%), free time (66%), and religion (65%). Good manners (90%), respect for others (77.1%), and responsibility (70.9%) were identified as the qualities to be promoted. Other important values reported were health and environmental protection.

Many of our customs are of Christian origin. One of the most important holidays is Christmas. It is celebrated from the end of November up to mid-January. Yes, we have the world record of celebrating the world’s longest Christmas season! There are many other Christian-related festivities, such as the Patron Saint Festivals, in almost every town. US holidays are observed, along with the local ones. National sports are also well celebrated. Those are occasions to gather with family and friends.

Gender and Sexuality

In modern Puerto Rican society, much progress has been made in values, attitudes, and stereotypes, although in certain sectors conservative, sexist, and exclusionary attitudes are still maintained. Although women play an important role in the family, our society is primarily patriarchal.\textsuperscript{14} Machismo and mariánismo are still part of our culture. This lack of gender equity manifests itself in a high incidence of violence against females and LGBTQIA+ groups. As per our neuropsychological work, this is a topic that requires sensitive exploration as family values might interpose its management.

Spirituality and Religion

Because of our Spanish heritage, the Catholic Church had a great influence on culture and our life in general. Most of the population identifies as Christians, or at least, believers in God. The rest practice other religions or are religiously unaffiliated.\textsuperscript{13} Other spiritual movements are identified in our cultural heritage, particularly from African origin mixed with Catholicism. Nuñez Molina’s studies\textsuperscript{15} have identified several movements: folkloric, evangelical, espiritismo, and santería. Even though they might function as a religion for some, they have been considered as a healing system, a philosophy, or a science for others.

Health

According to a recent cross-sectional study,\textsuperscript{16} there is a high prevalence of medical conditions among Puerto Ricans, including hypertension (39%), obesity (28%), arthritis (26%), hypercholesterolemia (24%), respiratory problems (21%) and diabetes mellitus (21%). The leading causes of death are similar to those observed in the United States: heart disease, cancer, diabetes, Alzheimer’s and cerebrovascular diseases.\textsuperscript{17} In youth, asthma is the most prevalent health condition.\textsuperscript{18} It is considered, however, that there are general health disadvantages when compared to the United States. Due to the high rate of migration and economic constraint, there are currently fewer specialty physicians and other health providers available for the population’s needs.

Mental Health Views

The prevalence of mental disorders in Puerto Rico is estimated at 16% in people between the age of 18 and 64, according to data in official documents of the government of Puerto Rico. The most
prevalent diagnoses in both youth and adults are affective and anxiety disorders (colloquially defined as **padecer de los nervios**). Substance use and dependencies disorders are also a public health concern. This data makes Puerto Rico the third largest jurisdiction in the United States with the greatest mental health problems. There is still some stigma associated with receiving psychological or psychiatric treatment, as it may be seen as “being crazy.” The deterioration of the economy, social inequality, poverty, limitations on access to mental health services, and recent natural disasters seem to have had psychological sequela with increases in cases of depression, anxiety, and suicides. In addition to the above-mentioned disorders, those factors exacerbated pre-existing conditions and sparked a wave of domestic violence.

**Approach to Neuropsychology in Puerto Rico**

We will present the following content from the perspective of three Puerto Rican neuropsychologists. All of us completed doctoral degrees in Puerto Rico, and two of us circulated to the United States for completion of post-doctoral fellowships in neuropsychology. We are all bilingual (Spanish/English), and currently work in both academic settings and private practice in Puerto Rico.

In Puerto Rico, as in many places in the world, neuropsychology is a new field. A recent study by Rodriguez-Irizarry and colleagues identified about 25 practitioners on the Island who considered themselves neuropsychologists. Here on the Island, neuropsychology follows the North American model of higher education and government licensure process. Currently, access to education related to neuropsychology on the Island is largely dependent on course offerings from doctoral training programs. This allows graduate students to receive basic training in harmony with some of the requirements of the Houston Conference Guidelines. However, the options for completing a predoctoral internship or postdoctoral residency in neuropsychology are very limited. According to the study conducted by Rodriguez-Irizarry, less than half of their sample (44%) completed a postdoctoral residency in neuropsychology. Professional training in neuropsychology represents a central controversy for the recognition or certification of this profession on the Island.

As happens in many parts of the world, particularly in Spanish-speaking countries, another challenge of our field is the lack of normative data for Puerto Ricans. At the time of writing this chapter, there were only a select group of tests developed or adapted for Puerto Ricans. Recent international efforts have provided some data of Puerto Rican norms for common neuropsychological tests. A common practice is to translate tests (if needed) and use available normative data from other countries. Others might use direct scores and personalized procedures through clinical practice. We try to manage this issue using the “process approach” in our evaluations, focusing on the qualitative data during procedures.

Obtaining local data is complicated, as research and publications are not often fostered outside of the academic setting. This is further complicated by the fact that the few practitioners on the Island are required to perform in many different scenarios and carry out several different duties, which lead them to become overburdened. Buying new tests and protocols can also be a challenge, as shipping and handling costs are higher than mainland United States and reimbursement and revenue from neuropsychological evaluations are significantly lower when compared to the mean average in the United States.

In Puerto Rico, there is little public awareness of neuropsychology and its contributions to the community. In our experience, even some physicians do not have knowledge of what a neuropsychologist does. Some people think we are neurologists. Many of the families we see have a basic understanding that neuropsychologists have additional training. Those of us with the pediatric
specialty have often been associated with neurodevelopmental conditions, and many of our referrals come from school personnel. There are many health-related conditions that we do not see as often as we should, such as epileptic syndromes and head traumas.

In general, we have found that, when working with families, the cognitive domains are not often the primary area of concern and discussion. Rather, the focus lies on obtaining a general picture of what they need in terms of intervention and case management and what is required to access the needed services.

**Section II: Case Study — “Too High Functioning To Be Autistic”**

Note: Possible identifying information and several aspects of history and presentation have been changed to protect patient identity and privacy.

Joel is a young man whom we have seen for services and consultations since he was 5 years old. This gives us the unique perspective of a longitudinal assessment. The family was part of the working class, from an area of Puerto Rico with a high percentage of poverty and, therefore, limited availability of services. We will be presenting background information and the results of Joel’s neuropsychological evaluations and follow-up consultations, together with the cultural and biopsychosocial challenges that he and his family have faced throughout their journey.

**Referral**

Joel is a left-handed Puerto Rican male from a small town located in the Southwestern part of the Island. He was initially referred to us by a family friend, who was a clinical psychologist, for a diagnostic evaluation. At that time, he was five years old. There were concerns regarding possible autism spectrum disorder (ASD) symptomatology. Per his mother’s report, the family had been reporting developmental concerns since Joel was 10 months of age and, while his neurologist and other specialists had noted symptoms of ASD, a formal diagnosis had not been established.

**Developmental History**

Joel was the product of an uncomplicated pregnancy and delivery. Mild delays in some motor milestones (e.g. holding his head and rolling) were reported, and Joel received physical therapy to support his development. Joel was able to walk at 18 months of age. In terms of his language development, he said his first words on time and was able to repeat songs that he heard on the TV, but his parents were concerned because he rarely responded to his name being called. He was evaluated by a neurologist and an audiologist, who found clinically negative results but referred Joel to a speech-language pathology evaluation, which identified language delays. Joel eventually began receiving speech-language therapy at age four. At the time of the evaluation, he was speaking both Spanish and English but, despite Spanish being the language spoken at home, he spoke and understood English better. Joel was also presenting with stereotyped speech at the time (e.g. referring to himself in the third person).

**Academic History**

Joel was enrolled in an educational daycare at two years of age. By age three he had learned to read and write on his own. He was enrolled in kindergarten when he was close to five years of age,
where behaviors such as frequent tantrums, ignoring instructions, refusing to work in the classroom, not staying seated, and not socializing with peers were reported.

Psychological and Behavioral History

Joel presented with restrictive and repetitive patterns of behavior, such as lining up toys, walking on his toes, avoiding stepping in between tiles, and pulling on his eyelashes; a history of hand flapping at age one was also reported. Joel was also reported to show inflexibility (e.g. insisting on following certain routines at home) and did not tolerate getting dirty. He was evaluated in a psychological clinic, where ASD symptoms were identified using the Gilliam Autism Rating Scale. However, a formal diagnosis of ASD was not made. He was only provided with intervention for toilet training.

Medical History

Joel suffered from dermatitis and nasal allergies throughout most of his life, for which he was treated with several different medications. He was hospitalized when he was one year old due to rotavirus and was later diagnosed with oxidative metabolic disorder and carnitine deficiency, for which he was treated with levocarnitine by his geneticist. His medical history was otherwise unremarkable.

First Evaluation: Five Years of Age

Joel was first evaluated by the authors at age five. General cognitive abilities were assessed using one of the few Spanish batteries available at that time: the Batería III Woodcock Muñoz (WM-III), Pruebas de Habilidades Cognitivas, as well as a nonverbal reasoning measure, the Raven’s Coloured Progressive Matrices, a developmental screener translated to Spanish: the DENVER-II, and a visual-motor integration task: The Bender Visual Motor Gestalt Test, Second Edition. Those were commonly selected tests in our clinic due to the Spanish language used for standardization, the amplitude of age ranges available, and the availability of norms that included a few Puerto Ricans among many other Latino communities in the United States.

Test results showed consistently average functioning in all areas assessed, including verbal comprehension, verbal knowledge, nonverbal reasoning, and visual-motor integration. However, throughout this evaluation and subsequent follow-ups Joel was found to demonstrate deficits in social interaction and communication, as well as restrictive/repetitive patterns of behavior, consistent with the DSM-IV-R criteria for High-Functioning ASD (identified at that time as Pervasive Developmental Disorder Not Otherwise Specified). This diagnosis came as a relief to the parents, who had for years been desperately seeking an accurate explanation for their son’s behavioral difficulties.

First Evaluation Follow-Up: The Struggle for Services

Following Joel’s diagnosis, the next step was for the family to obtain the recommended services for him. The family attempted to register Joel under the SEP of the Department of Education of Puerto Rico in order to receive services. However, he was initially denied services because he appeared to be “too high functioning to be autistic.” What came next was a struggle that is all too familiar for many parents with kids on the spectrum in Puerto Rico, and one that would last for many years: trying to obtain adequate services and accommodations for Joel inside and outside the classroom. At the same time, Joel’s parents felt that they were losing the support of many of their extended family members, as they did not understand his diagnosis and could not
understand why he had tantrums and sensory issues during family gatherings. These types of behaviors are commonly seen by the community as a consequence of “bad parenting” or “lack of discipline” to the child. The family had to stop attending social events and felt isolated from the social support that had been crucial for them in the past.

During this process, the family sought and found support from a relatively new, local advocacy group called the Autism Alliance. There, they met with parents who understood their struggles and were able to begin navigating the complex process of seeking services for Joel. Evidenced-based services for ASD were scarce, so the family found alternate interventions for Joel’s difficulties, including Auditory Integration Training, visual therapy, and a gluten- and casein-free diet. Joel’s mother learned as much as she could about his diagnosis and his rights under the IDEIA law and quickly became an active participant and a leader in the Autism Alliance, as well as a fierce advocate for Joel’s rights. Eventually, Joel was able to begin receiving services and accommodations under the SEP.

Joel remained in a regular education classroom, but behaviors such as tantrums and elopements made it necessary for him to receive the support of a one-to-one aid. With this support, problem behaviors were significantly reduced and, by the second grade, had ceased to be present. During this period, Joel was noted to begin talking with and having lunch with classmates.

**Second Evaluation: Psychoeducational Evaluation at Seven Years of Age**

At the time of his second evaluation, Joel was enrolled in the second grade. He was motivated and performing well academically, with strengths in classes related to English and Mathematics. His aid helped with redirection and facilitated his comprehension of instructions. Behavioral concerns at school included falling asleep in class, taking off his shoes, and complaining of itching on his body. Testing was carried out in Spanish, and, because of his age and the recent publication of more Spanish instruments, we were able to administer the following tests: Wechsler Intelligence Scale for Children - IV - Spanish (WISC-IV-Spanish), Ravens Coloured Progressive Matrices, WM-III, Bender Visual Motor Gestalt Test, Human Figure Drawing, a School Behavior Checklist, Child Behavior Checklist (CBCL), and the Behavioral Rating Inventory of Executive Functions (BRIEF).

During testing, Joel was cooperative and followed instructions. He would make spontaneous comments about his favorite videogame characters and respond to direct questions with phrases or short sentences. He had difficulties answering verbal test items and often responded by talking about topics not related to the question being asked. Not surprisingly then, verbal tests were found to be more challenging for him than visual and visual-spatial tests. On the WISC-IV-Spanish, his performance fell in the average to above-average range in visual, visual-spatial, and visual-motor tests but fell in the low average to below-average range on verbal reasoning tests. He was found to present with difficulties in executive functions (e.g. initiation, working memory, cognitive organization, and flexibility). Academically, his reading, writing, and math skills, as assessed with the WM-III, were within age- and grade expectations. Consistent with his ASD diagnosis, continued difficulties in social interaction, imaginative play, social communication, as well as restrictive/repetitive patterns of thinking and behavior were documented.

**Second Evaluation Follow-Up**

Following the evaluation, Joel began to receive psychological intervention to support his socio-emotional functioning, in addition to speech/language therapy (SLT) and occupational therapy (OT). These services were provided as “related services” by the SEP. Because the therapies were frequent throughout the week, were provided outside the school setting, and many of
them were provided after school hours, Joel’s parents were feeling overburdened and were missing workdays too often. They enlisted the help of their eldest daughter and some close friends in providing transportation for Joel to and from school and therapy centers.

**Third Evaluation: Neuropsychological Evaluation at Nine Years of Age**

At age nine, Joel continued to receive SLT, OT, and psychological intervention; he also received visual therapies. Medically, he was being treated with cetirizine for allergic dermatitis and with levocarnitine for metabolic deficiency. With regards to schooling, he was in the fifth grade within a regular education classroom (in Spanish), where he had the support of his one-to-one aid. He presented with sleepiness in school and required a ten-minute nap during the afternoons. He showed difficulties understanding and following directions and remembering to hand in assignments, as well as difficulties with writing and low frustration tolerance. Socially, he enjoyed relating to others, although pragmatic difficulties persisted, as well as compulsive patterns of behavior, obsessions, and rituals. He presented with difficulties organizing language and using vocabulary adequately, although he performed better when speaking in his preferred language, English.

He was assessed using the following tests: WISC-IV-Spanish, Wechsler Abbreviated Scale of Intelligence, Vocabulary Subtest (to assess his English expressive language skills); Tower of London; Trail Making Test; Rey Osterrieth Complex Figure; Beery Developmental Test of Visual Motor Integration; Test de Aprendizaje Verbal Infantil; as well as selected subtests from the Test of Everyday Attention for Children; Evaluación Neuropsicológica Infantil; NEPSY-II; Test of Auditory Processing Skills, Third Edition, Spanish-Bilingual (TAPS-3). The following behavior rating scales were also completed by his parents and teachers (when applicable): ADHD Rating Scale; BRIEF, and Behavior Assessment System for Children, Second Edition (BASC-2 PRS-C).

Joel’s neuropsychological profile continued to reflect average-level intellectual abilities, as well as average-level functioning in most other areas assessed. Persistent weaknesses were documented in his executive functions (particularly in cognitive organization and flexibility), language, and fine motor skills. Notable progress was documented in his social skills, although weaknesses in pragmatics persisted (e.g. maintaining conversations, understanding sarcasm). What was particularly striking within the results of this evaluation was how different his language performance was in English when compared to Spanish tests. His understanding of instructions in English was age-appropriate, but he struggled with comprehending instructions in Spanish, which meant that he needed most instructions to be translated to English for him. His performance on the English vocabulary test fell in the average range, while his performance in the Spanish vocabulary test fell well below average. Additionally, difficulties with his production and organization of language were noted when he spoke in Spanish but not in English. He was even speaking in Spanish using English syntax and structure. Due to these difficulties, we included in our recommendations a particular emphasis on allowing him to use English to respond to questions while at school and for school personnel to use language that Joel could understand within this setting while providing direct intervention to help him further develop his language competencies.

**Third Evaluation Follow-Up: The Language Barrier**

Joel was attending a Spanish-language public school, and it was difficult for school personnel to implement language recommendations, as some did not possess the needed proficiency in English to be able to communicate with Joel in this language. Because he appeared to be so high functioning, many also underestimated his language comprehension difficulties. Joel was struggling with academic demands in Spanish. He also encountered frequent social, or pragmatic,
misunderstandings. For example, on one occasion, he did not hear the class bell ring because he was in the library (avoiding the sensory overload of the playground noise). When he arrived late to class and explained this to his teacher, his teacher replied saying that it “was no excuse” for arriving late to class. Joel then proceeded to insist on genuinely explaining to the teacher that it was, indeed, an excuse, not understanding what the teacher really meant (that his excuse was unacceptable and that he should not have been late for class). An argument ensued and Joel was sent to the principal’s office as a disciplinary consequence, as he “defied” and “spoke back to” an authoritative figure (which is not appropriate behavior for a child in our culture). Meanwhile, his parents continued to struggle to obtain an adequate school placement for him. They persevered in making adjustments and sacrifices to be able to provide him with the support and intervention that he needed.

Fourth Evaluation: Neuropsychological Re-Evaluation at Age 12

At age 12, Joel was seen for a re-evaluation and update on recommendations. Now in sixth grade, he continued to be enrolled in an all-Spanish regular education classroom in public school, with the support of a one-to-one aid. Continued difficulties with attention, executive functions, compulsive behaviors, and hypersensitivity to noise in crowded classrooms and hallways were reported. Additionally, he was reported to pull his eyelashes out when anxious. Medically, he was being treated with antihistamines and topical steroids to treat his persistent dermatitis. Except for visual therapy, he continued with all other therapeutic services as provided through the SEP.

For this evaluation, all the tests (in both Spanish and English) from the neuropsychological battery administered at age nine were repeated. His cognitive profile appeared to be relatively stable; however, his performance on English and Spanish language tests seemed to even out, with improved performance on Spanish-language tests. Because of continued fine motor difficulties affecting his performance on writing-based tasks, an additional diagnosis of dysgraphia was established.

Third Evaluation Follow-Up: The Language Barrier

Despite his improved performance on Spanish cognitive tests, Joel continued to prefer speaking in English, demonstrated greater fluency when using said language, and struggled with school in Spanish. The family had fought in vain to procure for him accommodations that would allow for the translation of school materials to English. Like many adolescents with ASD, Joel’s difficulties began to lead to mood and anxiety issues, for which he was seen by a psychiatrist. Meanwhile, his mother had seen her own health deteriorating and had not had the time to seek medical assistance until her condition became aggravated. She was later diagnosed with a neurodegenerative disease that also needed special care.

Fifth Evaluation: Psychoeducational Re-Evaluation at Age 13

Because of his continued struggle in academic subjects, Joel was brought in for a psychoeducational evaluation the following year, at age 13. By this point, he had been diagnosed with anxiety, depression, and obsessive-compulsive disorder and was under treatment with sertraline and dexamphetamine hydrochloride, prescribed by his psychiatrist. He continued to pull out his eyelashes during periods of anxiety or frustration, and difficulties maintaining sleep at night were reported by his mother. Treatment with antihistamines for allergies and dermatitis continued. Although he had friends in school, continued difficulties with pragmatics and making new friends were reported. Academically, he benefitted from the assistance of his one-to-one aide but showed
difficulties in reading comprehension, particularly in Spanish, as well as in writing, consistent with his diagnosis of dysgraphia.

The following battery of tests was administered: WM-III, select subtests; Woodcock-Johnson III: Tests of Achievement and Tests of Cognitive Abilities (WJ-III), select subtests; Grooved Pegboard; NEPSY-II: Fingertip Tapping subtest; Dean Woodcock Sensory-Motor Battery: Coordination subtest; TAPS-3, select subtests; BRIEF, parent and teacher ratings; BASC-2 SRP; CBCL; and a School Behavior Checklist.

Like before, testing accommodations had to include translation of Spanish instructions to English to aid in comprehension. Select subtests from both the WM-III (in Spanish) as well as the WJ-III (in English) were alternately administered to compare his oral and reading comprehension, as well as expressive vocabulary in each language. Results showed notable strengths in English comprehension (oral and written), as well as English reading and writing fluency when compared to his performance on Spanish measures. Persistent weaknesses in executive functions and fine motor coordination were noted. Based on the results of this evaluation, it was recommended that Joel be placed in a bilingual (English-Spanish) regular education classroom or, at the very least, that translation to English be provided for instructions and academic materials.

Follow-Up

Having vast evidence to support their claim that Joel needed English-based accommodations, his parents hired a lawyer and embarked on a legal claim with the Department of Education. After a struggle to find the appropriate placement for him, his school finally decided to open a small group (10–11 students) bilingual classroom (English and Spanish) for talented students. This was a great benefit, not just for Joel but for other regular and special education students who were academically motivated and interested in being educated in English. Joel continued receiving the assistance of a one-to-one aide to help manage symptoms of anxiety (such as panic attacks), as well as social challenges. Within this setting, Joel thrived and was able to graduate high school.

Beyond High School: A Hurricane, a New Struggle and a Move

After successfully completing high school, Joel had planned to attend college. However, the process of transitioning from the SEP to the Vocational Rehabilitation Program for adults proved to be lengthy and unfruitful. Although Joel had a legal right to receive transition services and supports, including counseling to help him through this process, he did not receive it on time and was left in his home for a full year, having a drastic change in his routine, and without being able to pursue his goals. During this time, a catastrophic hurricane struck Puerto Rico and, not only was Joel stuck at home, but he was also experiencing the stress caused by the aftermath: spending months without reliable electricity and/or water. This led to a regression in symptoms, as described by the family. Joel became increasingly depressed and anxious, his panic attacks increased, and he stopped eating, which led to significant weight loss. Because of this, and like many other families in Puerto Rico at the time, the family decided that it would be best to relocate with their eldest daughter’s home in the United States. Once there, they quickly retook the process of enrolling Joel in a Vocational Rehabilitation program. There, Joel received job and interview training and was able to obtain employment in the fast-food industry within the first months after moving. At the time of writing this chapter, we were able to communicate with Joel and his family. Joel is happy, healthy, and thriving. His family seems to be in a healthy
Section III: Lessons Learned

- Puerto Rico is a colonized country, for centuries from Spain, and over the last century from the United States. Culture and traditions come mostly on a mixture of African, European, and, probably less often, Native American descendants, with the Spanish language being one of the most prevalent heritage. The influence of the North American culture is also taking part in our culture.

- Even though Puerto Rico is a territory of the United States and uses the same health system and education model, public services are not necessarily optimal for timely preventive care. Bureaucracy and economic policies seem to affect health care access.

- There are as many Puerto Ricans on the Island as they are outside of the Island, particularly due to migration movements in the 1960s and 2000s. Most of the migration is to the United States, as people from Puerto Rico were granted US citizenship in 1917. This is a relatively accessible option for Puerto Rican families in need of health, education, employment, and economic opportunities. Moreover, most families already have a family member or friend who has already migrated. Despite assimilation and acculturation processes, Puerto Rican culture is usually maintained.

- Families often move to the United States looking for a better quality of life or seeking needed services for one or more of its members. This happened to Joel’s family when he grew up: services were not immediately available for him after graduating high school, and the limited services available were scarce after the aftermath of natural disasters. In addition to representing our family-centered culture, this event also highlights the need for professionals to develop research and promote public policy to assist in the services that children with neurodevelopmental disorders might need when they grow up.

- Neuropsychology is a new discipline in Puerto Rico. There are few neuropsychologists on the Island, and the field is often not recognized in the community. There is a limited culture for research in the profession, in part, because of the few researchers and their many work duties. Consequently, as happens with many Latin American countries, there are few tests available for Puerto Ricans.

- Autism Spectrum Disorder recently started to be in public awareness, as has happened in many parts of the world. Because of the extensive research conducted over the last three decades, new definitions and classifications have been updated, but not all health and education professionals are aware of these. In places like Puerto Rico, identifying what at one point can be considered a rare disease can be challenging. With Joel, there was a denial from health professionals and teachers of him having ASD, as he was “too functional to be autistic.” This was a common myth even when the DSM-IV definition was commonly used.

- Spanish is the language predominantly used in Puerto Rico. However, a common phenomenon seen within the ASD population is a preference for speaking English. There is some limited work regarding that topic. It seems that it is possibly due to frequent exposure to the English language through videos and games on electronic devices (since a very young age) and/or to reduced grammatical demands and rules in English when compared to the Spanish language. Therefore, neuropsychological evaluations in Puerto Rico, particularly in ASD, require taking into consideration the dominant language of the individual. This might impact the selection of language and test use.

- Test selection in general will continue to be a long-term dilemma, given the limited availability of tests specific for the Puerto Rican population and relatively easy access to tests published in
the United States. Decisions must be made on whether to use a test that is normed in another Spanish-speaking country or to use tests that have been translated from the English language but not adapted or standardized to our population. The decision seems to go beyond formal testing, as it also might impact the educational placement.

- A caring attitude and familiarity are positive attitudes often seen in Puerto Rican families. Joel was able to attend school and receive services because the parents were supported by their daughter, friends, and some extended family members. Some teachers were also helpful. Likewise, the family managed to establish a healthy, and somewhat a familiar, professional relationship over time with us.

- Family needs and diagnosis awareness are often prioritized. This might go beyond the classic practice of neuropsychology. Even though Joel was evaluated within the context of a neuropsychological evaluation, the major concerns were the lack of awareness of the condition in the community and family members, the lack of support from the educational system due to lack of knowledge, and the struggle to get the services he needed. This family in particular took the initiative to become active leaders in supporting many other families in the process of managing autism through the health and education system. The process to obtain services in Puerto Rico is very slow. Therefore, the practice of pediatric neuropsychology in Puerto Rico requires the clinician to be knowledgeable of how the education and public system in general work. One of our many duties in the clinical practice includes becoming case managers.

**Acknowledgments**

We would like to provide special thanks to Joel and his family for their availability and willingness to collaborate with us in narrating Joel's journey, despite being outside the Island.

**Glossary**

- **Espiritismo.** Spiritism. It is a movement or a belief that spirits can affect health, luck and other aspects of human life.

- **Machismo.** It is a sense of masculine pride and dominance, commonly seen in Latino cultures.

- **Marianismo.** It is the expectation for females to be passive, submissive and dedicated to the home and family. It is very common in Hispanic communities.

- **Padecer de los nervios.** Suffer from the nerves. It is a common name used by Puerto Ricans to describe ambiguously psychiatric disorders.

- **Santeria.** The way of the saints. It is a religious practice of African origin, based on the personal relations between deities, or saints.

**References**

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