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Understanding Early Intervention Services for Hispanic Children with Autism Spectrum
Disorders

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Program in Communication Disorders

Honors Thesis

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Abstract

Clear communication between speech-language pathologists and their clients and client's families is essential for the success of therapy. A common language between therapist and client also facilitates the exchange of information, however this is not always possible. The purpose of this study was to develop a Fotonovela as an informative tool for Hispanic parents with children in the autism spectrum to use as an early intervention guide, to provide information on therapy services and to promote the understanding between professionals and culturally diverse populations. A Fotonovela is a pamphlet with photographs in the comic-book format that usually depicts a story with a soap-opera type plot with short dialogue bubbles. The Fotonovela created was adapted to serve as an informative tool for families and speech-language pathologists working with culturally and linguistically diverse populations. The booklet focused mainly on a basic depiction of the diagnostic process beginning with commonly known symptoms of autism, then it depicted three commonly used early intervention therapy techniques for ASD that were found useful from evidence based practice research. The therapy techniques were described in a simple manner in order to reach low literacy Latino audiences. A second product was also created as a companion piece of an online document offered by the Autism Speaks website. The purpose of this piece was to simplify a lengthy document into a simple and user-friendly introductory booklet for the benefit of low literacy Latino families as well. It was originally created in Spanish and then translated into English for the benefit non-Spanish speaking families and professionals.

Valuing Cultural and Linguistic Diversity in Hispanic Children with
Autism Spectrum Disorders

The research evaluating the difficulties and obstacles of culturally and linguistically diverse families with children on the autism spectrum is fairly limited. However, some findings show that language and cultural differences in ASD populations cause inherent obstacles in therapy and treatment. Often, language barriers create a serious disadvantage for immigrant populations and “negotiating treatment procedures takes time and can be quite frustrating, particularly with families who are new to intervention systems” (Welterlin & LaRue, 2007, p.754). We also know that the services offered to multicultural families are scarce because “ASHA certified bilingual speech language pathologists are rare in the profession”(Kayser, 1995, p.2). Since there is a clear shortage of available bilingual speech-language pathologists able to conduct appropriate assessment, diagnosis and treatment for culturally and linguistically diverse populations, we must start by bridging the gap of cultural and linguistic difference. One way of filling this existing knowledge vacuum is through the development of culturally sensitive informational tools such as the Fotonovela to provide information to the target populations. The purpose of this study is to develop a Fotonovela as an informative tool for Hispanic parents with children in the autism spectrum to use as an early intervention guide, to provide information on bilingual services, and to promote the understanding between professionals and culturally diverse populations. Through the Fotonovela, therapists will be able to better communicate common goals of therapy and promote understanding of the profession in a culturally sensitive way.

Review of the Literature

Overview of Autism Spectrum Disorders

Since the 1980's, the prevalence of Autism Spectrum Disorders in the United States has shown a dramatic increase since the 1980's (Strock, 2008). However, a debate argues on whether there has been a true increase in the prevalence of autism. There is reason to believe that the change in the criteria in which the disorder is diagnosed, "along with increased recognition of the disorder by professionals" (p.4) may be contributing factors to the increase of prevalence of this disorder. Strock (2008) explains that in 2007, the Center for Disease Control estimated that 1 in 150 children have a disorder in the Autism Spectrum.

Autism is a neurologically based developmental disorder that affects multiple levels of functioning and areas of development. Research shows impairments in these specific three areas of functioning: communication, sociability and behavior. Individuals that have difficulties with different levels of these areas of normal functioning are known to fall under the Autism Spectrum. The disorders found under the spectrum are: Autistic disorder, Asperger's Disorder, Childhood Disintegrative Disorder (CDD), Rhett's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). In the communication domain of the triad of impairments, individuals who fall within the spectrum have difficulty in the area of language, especially in language use and pragmatics, which are the rules in which we use language to communicate. In the social domain, these individuals will lack social skills to interact with the world around them. They will have difficulties in "recognizing other's intentions, beliefs, thoughts, and knowledge of feelings" (Kremer-Sadlik, 2005, p. 1227) thus greatly hindering their

capacity to create and sustain long lasting friendships and relationships. The third area that affects the normal functioning of individuals with an ASD is behavior. Individuals will demonstrate restricted interest in one topic or activity and will display stereotypic repetitive behaviors such as temper tantrums, screaming, or head banging.

Autism spectrum disorders are usually diagnosed by a team of health care professionals such as pediatricians, neurologists, speech-language pathologists, and occupational therapists among others (ASHA, 2013). Once diagnosed, the importance of early intervention strategies is highly stressed to the families. Speech-language pathologists will then evaluate the child's social skills and communication needs before beginning early intervention (ASHA, 2013).

Multiple methods of therapy have been used to treat individuals with ASD. However, since each individual with ASD can display varying symptoms and behaviors along the autism spectrum continuum, specific interventions and treatment must be tailored to that individual. Types of treatment may include "any combination of traditional speech and language approaches, augmentative and alternative communication, and behavioral interventions"(ASHA, 2013). Due to the numerous and distinct forms of treatment offered for ASD, it would be necessary to create a Fotonovela uniquely tailored for each individual's needs and goals. For the purpose of this study, the Fotonovela created will focus on some of the most common and widely used therapy techniques for early intervention and the role of the speech-language pathologist and family in the early intervention process.

Increase in Cultural Awareness

The apparent increase of prevalence of these spectrum disorders has raised awareness of the importance of early interventions therapies to support the future functional development of these individuals. However, despite this increasing awareness, “little is known about the impact of cultural and linguistic diversity on interventions to support communication development in children with autism” (Trembath, Balandin, & Rossi, 2005, p. 240). The article “Serving the needs of immigrant families of children with autism” also notes that “few studies have documented the ways in which autism spectrum disorders (ASD) are understood across different immigrant groups” (Welterlin & LaRue, 2007, p.747). Consequently, cultural differences might influence the “way diagnosis, etiology and treatment of ASD is perceived by both immigrant families and western practitioners”(Welterlin & LaRue, 2007, p.747) therefore creating obstacles in treatment for the professionals and miscommunication with the parents. Seung, Siddiqi, & Elder (2006) also recognize that, “to date, little has been reported regarding how to design interventions” (p. 53) for children with autism that are culturally diverse and live in bilingual homes.

Research in Bilingual Therapy in ASD

It is evident that there is growing necessity for clinical advancements in therapies and research regarding individuals with Autism Spectrum Disorders with diverse cultural and linguistic backgrounds. As Seung, Siddiqi, & Elder (2006), Trembath, Balandin, & Rossi, (2005) and Welterlin & LaRue, (2007) all determined, there are very limited resources guiding clinicians on how to efficiently implement treatment interventions while taking into consideration cultural differences.

Toppelberg, Snow, & Tager-Flusberg (1999) offer clinical reflections on whether or not it is beneficial or even possible to teach a child with ASD a second language in order to preserve “the home language in language-minority children” (p.1199). The authors question whether or not second language exposure will have cognitive advantages on children with developmental disorders as their typically developing peers would. To able to determine such question, (Toppelberg, Snow, & Tager-Flusberg, 1999) first addresses “(1) the importance of quality of language input in determining functional linguistic outcome in the child with DD and (2) the need to secure high- quality language input for the acquisition of a second language (L2)”(p. 1199). To conclude, the authors offer clinical advice on how to determine whether or not an individual with a developmental disorder should be exposed to a second language, factors influencing the success of exposure such as parents proficiency in the second language, and the child’s particular “attitude towards and aptitude for language in general” (Toppelberg, Snow, & Tager-Flusberg, 1999, p. 1199).

Bilingualism in Autism

A survey of bilingualism in autism spectrum disorders studied “parent perspectives on bilingualism, choices they make regarding bilingualism for their children with autism, the reported success with bilingualism their children with autism experience and the advice received from professionals regarding bilingualism”(Bird, Lamond, & Holden, 2012 p.52). In North America, parents with ASD children will often be “counseled away from exposing their children to a second language”(Bird, Lamond, & Holden, 2012 p. 52). However, such advice is not always plausible because of the importance for the individual to learn to communicate in different languages in order to

be an active participant of his/her community, “bilingualism, therefore is not a choice but a necessity” (Bird, Lamond, & Holden, 2012, p. 52) for such individual.

Kremer-Sadlik (2005) also mentions that “parents whose native language is other than English indicated that they were advised upon diagnosis of autism in their child to speak only one language to their child, namely English regardless of the parent’s English proficiency”(p. 1225) agreeing with Bird, et al (2012) statement that parents were being counseled away from bilingualism. However Kremer-Sadlik, (2005) states that “there is no sufficient support for the claim that multilingualism further harms language acquisition of language impaired/delayed children” (p. 1232), this statement might argue that discouraging second language acquisition by some professionals might not be tenable. To conclude, Kremer-Sadlik (2005) states that “children brought up in multilingual, multicultural [societies]” must be given the “opportunity to learn both their mother tongue and English” (p.1232).

Understanding Cultural Influences

One of the obstacles with culturally diverse autistic children is whether or not to limit their language to only one. Some researchers argue against a second language acquisition while others argue for it. However, it is up to the individual’s family and clinicians to decide on the bilingualism aspect of therapy. Clinicians also need to take into consideration how different cultural and linguistic backgrounds will directly affect the treatment methods and outcomes. Trembath, et al, (2005) and Welterlin & LaRue, (2007) both discuss the importance for health care providers to consider the role of culture in diagnosis and treatment. In their article, Trembath, et al, (2005) explain how “cultural and linguistic background may impact on the use of Augmentative and

Alternative Communication (AAC) Systems” (p. 240) and therefore a clinician might have to “consider other strategies that support learning and that are influenced by culture” (p.241). Similar reflections are offered by Welterlin & LaRue (2007) mentioning health clinics “that specialize in diagnosing and treating ASD are limited in their capacity to provide appropriate cross-cultural services” (p. 749). Most practitioners that are educated in western universities lack that ability and knowledge to provide adequate treatment for individuals with diverse cultures and backgrounds, therefore it is important that clinicians seek special training in order to better “navigate issues related to cultural differences in treatment settings” (Welterlin & LaRue, 2007 p. 749).

Importance of Parent Involvement

Parental involvement in and out of the therapy room is essential to the progress and development of a child with autism spectrum disorders. Parents have to become cotherapists to continue the therapy goals outside of the therapy session. It is therefore important that the therapist and the parents of the client develop a relationship in which the therapists can communicate the clear goals of therapy to the parents. It is then the parent’s responsibility to continue to address the same goals at home to increase the effectiveness of therapy.

The use of Fotonovelas for Education Purposes

Fotonovelas were initially developed as comic books widely recognized by the Latino population. They were usually used for entertainment with a soap opera plot reflecting social or cultural issues (Chapin, 2008). Recently, there has been an emerging use of these comic book style pamphlets to educate and promote awareness of health

issues in the Hispanic population and have proved to be valid. A study conducted at USC School of Pharmacy with a Fotonovela providing awareness for diabetes in the Hispanic population showed that it “successfully increases diabetes awareness and knowledge in the Latino community” (Chapin, 2008). The Fotonovela not only provides an entertaining source of information, but it is developed as a tool to aid better understanding for the target population and shows that “the cultural relevance of the story in the fotonovela really helped participants connect more with the issue” (Chaplin, 2008). The use of a fotonovela to educate the population about health issues has been proven to be effective in health related areas.

Need for Further Research

The immigrant population in the United States is rapidly increasing thus increasing the prevalence of culturally and linguistically diverse individuals with autism spectrum disorders. According to the literature, problems are arising because of the increase of bilingual and culturally diverse environments. Clinicians are unsure whether or not bilingualism is beneficial or detrimental to the greater development of an individual with an ASD. While some cross-cultural studies show that bilingualism is an attainable goal for specific individuals, others strongly discourage exposure to a second language in fear that it might confuse the development of a first language as well as other concurrent developments. These individuals also face extreme cultural and social barriers that need to be taken into account by clinicians in order to offer more effective and appropriate therapy. Since the world is becoming more multicultural and multilingual everyday, there is a growing need for more substantial literature “addressing the experiences of recent immigrant families of individuals with autism spectrum disorders in

the USA” (Welterlin & LaRue, 2007, p.748). Without this knowledge, “professionals and families are forced to work in a knowledge vacuum”(Trembath, Balandin, & Rossi, 2005, p. 241). Further research should focus on the development of culturally sensitive techniques or tools to be used by professionals for their culturally diverse clients as well as further examine bilingual therapy and ASD populations.

Summary

Autism spectrum disorders are neuro-developmental conditions that impact children from all backgrounds. Families from different cultural background are often faced with decisions about services for their children with ASD that is complicated by language barriers. They are also often discouraged from speaking their native language and are treated in English because of the lack of multicultural services available. Most early intervention and special education services are provided by English speakers assisted by translators, which can complicate decisions and most importantly hinder the families’ possibilities and desires to raise their child with ASD as a bilingual speaker. More often than not Spanish speaking families will find themselves with language barrier based problems when communicating with English speaking professionals. The purpose of a Fotonovela adapted for Spanish speakers was to break those communication barriers between the clinician and the family and to provide a tool that introduces early intervention services for Hispanic families with a young child with ASD.

Project Description

Products

Two products in two languages were created for the purpose of this project. The first product was created as a companion piece to a document on the Autism Speaks website that serves as a “100 Day Kit” for parent’s of a recently diagnosed child. For more information to obtain this kit, available in both English and Spanish, go to: (<http://www.autismspeaks.org/family-services/tool-kits/100-day>). The reason for creating a companion piece was to offer an introduction to a lengthy document and to highlight the important elements that take place during the diagnosis of autism. Therefore, both an English and Spanish product was created to assist parents and professionals who may have varying literacy skills in one of the two languages.

A Fotonovela style booklet written in Spanish and translated into English was the second product developed within this project. Fotonovelas, or comic book-style pamphlets, are used to reach persons with low literacy skills in an entertaining yet informative way (www.rwhp.org/fotonovela-ed-tool.html). Using Fotonovelas to provide awareness about health related issues has proven to be a very effective way of conveying important information to the Latino population. The purpose of this project was to produce such a product in both Spanish and English that utilized evidence based practices to provide helpful information about the diagnosis of autism and proven early intervention services to parents with children on the autism spectrum. The target population was primarily Latino families, but the product was also translated into English

so therapists with limited Spanish would better be able to use it with these families. In addition, the English version could be used for English-speaking families..

A literature review of early intervention programs for autism provided extensive information on early intervention programs that have proven to be effective including “empirical evidence for certain intervention strategies” (Corsello 2005, (p 75). The article included a review of many birth-3 early intervention programs for autism as well as pre-school programs that have also been effective. This was a helpful source to determine which early intervention programs to include in the Fotonovela. The main focus while creating this product was keeping it simple, user friendly and optimistic while providing useful information about the different types of interventions available.

In summary, two different informational pamphlets were created in this thesis project. One of these was based on an existing, well-documented, and referenced document currently on the Autism Speaks website while the other was created by the author of this thesis project from the research literature that highlights identification and early intervention. Separate informational pamphlets and novellas written in Spanish and English were produced. These can be found in the appendices of this thesis.

Process

The process of developing these products was an ongoing editing and creative. Keeping it simple while conveying complex and important information was a definite challenge in the creation of both the pamphlet and the Fotonovela. A description of the process of the creation of these materials follows.

The first product created was the Fotonovela. The first step to developing the product was looking on the web for examples of Fotonovelas that have been previously

created for education purposes. The Fotonovela website (www.rwhp.org/fotonovela-ed-tool.html) offered a comprehensive description of what Fotonovelas are and included examples of previous Fotonovelas used in health care awareness campaigns as well as helpful information on how to create your own. This website also offered sample Fotonovelas available to the public in order to get a general idea of the format of what a Fotonovela looked like and what it included. Usually a Fotonovela provides “realistic options or solutions to issues” (www.rwhp.org/fotonovela-ed-tool.html) and educational tool to convey important health messages. One of the challenges of this process was selecting the information that was going to be included into the final product. The basic outline of what was chosen to be included into the Fotonovela was: a brief definition of autism, the diagnostic process describing the professionals that play a role in the diagnosis and information about three early intervention programs chosen from a review of the literature.

The next step in the process was determining what the plot of the story would be and what characters were important to include. A simple plot was developed including two parents who express their worries about their young son to a pediatrician while describing common symptoms of autism. A review of the literature and the Autism Speaks website was used as a guide of the common symptoms and behaviors of children with autism.

Next came a basic depiction of the diagnostic process that includes a picture of an inter-professional team of health care professionals that are most likely to be involved in the diagnosis of autism. It was important that the Fotonovela show the parents taking action after the diagnosis in order to highlight the importance of family involvement in

the treatment of autism. The two parents were depicted in a scene with dialog explaining the importance of early intervention services and becoming actively involved in their son's life. The third and final aspect of the story included a friendly speech language pathologist that provided the family with important information about early intervention programs. The main purpose for the character of the speech language pathologist was to show that the professionals who will work with the parents and their son are very helpful throughout the process and should be friendly and easily approachable. It was important to transmit a sense of hope and optimism to the reader through the use of encouraging comments for the speech pathologist and the provision of simple yet helpful information.

After the basic plot and characters were decided, next came the actual creation of a rough draft on PowerPoint including an outline of what each page would include. The outline would included: A basic description of the disorder, the professionals involved in the diagnostic and information on early intervention programs with examples of early intervention techniques that the research has proved to be effective, This was followed by an overview of the contents that was to be included at the beginning of the novella to give a clear description of what was to be covered. A very basic definition of autism and its characteristics was put as an introductory page followed by the beginning of the story depicting the parents of a two year old child who were worried about their son's unusual habits and behaviors. After the plot was decided, the creative process of adding the actual dialog and pictures took place. The dialog bubbles were written for each section of the Fotonovela, and then photos were chosen from the Internet to represent the characters.

In order to capture the reader's attention, the Fotonovela was designed in a colorful comic book style with bubbly letters for the text. The playful design and pictures

with smiling characters was an important aspect of the creation of this product since the purpose was to entertain the reader while providing useful information that could give some insight into the complicated process of diagnosis and intervention of autism spectrum disorders.

The final step of the process was to translate the text from the original version in Spanish to an adequate representation of it in English. Instead of creating a full new document and starting with blank pages, the same document was used and a native Spanish speaker with proficient English writing skills translated the document.

The second product created was a companion piece to an Autism Speaks document that provides extensive information about the first 100 days after a diagnosis of autism. The information to be included in the companion Autism Speaks document was straightforward and directly linked to the online documents, each of more than 50 pages, that parents and professionals could read online. This informational pamphlet differed from this first document in that it was an original creation of the author based on research literature. The main focus for the creation of this product was to simplify the lengthy fifty-page document offered online into a quick and easy to read introduction. The purpose of this was to provide a valuable introduction to the diagnosis of autism in a less overwhelming way. The main focus audience was also for low literacy Latino families who could perhaps have access to the original document but didn't have the necessary literary skills to read such a complex document.

The first step in making this companion piece was deciding what information was considered most relevant to include in the final product. After having read the extensive "100 day Kit", the creator of the companion piece pulled out relevant information on

therapeutic techniques most often used in the treatment of autism. This information was then portrayed in a simple and easy to read manner. The document was created in Spanish and then translated into English for the use of English speaking clinicians as well.

The final documents (contact Valeria Font valfontzor@gmail.com for copies) were reviewed by professionals in the areas of speech-language pathology, special education, and counseling/leadership of autism programs. Feedback from these professionals was used to edit and amend various drafts until the final products of this thesis were completed.

Discussion

The purpose of this honors project was to make a product in the form of a Fotonovela adapted for Spanish speakers to break inherent communication barriers between the clinician and the family and to provide a tool that introduces early intervention services for Hispanic families with a young child with ASD. As can be seen, the review of the literature revealed that the evidence for parent involvement in the diagnosis and early treatment of children with autism spectrum disorder is vital for pushing development forward. Major complications for Latino families include limited resources in Spanish, a lack of participatory ownership of the diagnostic and intervention process, and the lack of bilingual speech-language pathologists to serve Latino families. To contribute to solutions for these issues, two informative documents – one an informational pamphlet and the other a Fotonovela – was constructed for this honors project. A discussion of these projects, in light of evidence based practice, and their potential future follow.

Linguistic and cultural differences create significant barriers when it comes to evaluation, diagnosis and treatment in the health professions. Most health professionals educated in western universities lack the ability and knowledge to provide adequate treatments to culturally diverse individuals (Welterlin & LaRue, 2007). The lack of cultural and linguistic sensitivity makes it very difficult for families who don't speak English to reach out to these professionals for help. It also puts the professionals at a disadvantage for not being able to communicate clearly with their patients. The language barrier hinders the exchange of information between the therapist and the client.

In order to attempt to bridge this linguistic barrier, the two products of this honors project were conceived and produced. These included an informational companion pamphlet to an Autism Speaks website document and a Fotonovela based on research literature that was created to serve as an informative tool for both health care professionals that work with Hispanic children with ASD and their families. The development of these two documents, their translation between languages, and editing by speech-language pathology and autism studies professionals were demanding yet exciting activities. Time limitations did not allow for field-testing of the materials. This leads to the limitations and future directions rooted in this project.

Limitations

One of the limitations of the study was that the informational pamphlet and Fotonovela were not used to gather data. Since the creation of these informational documents was an extensive task, the actual creation of the product took the majority of the time allotted for the thesis project. In addition, once developed, each of these had to be translated into English. This did involve reading of materials by professionals familiar

with autism spectrum disorder. Changes to both documents followed from this. Another limitation of the study was that more products could have been created to show every step of the evaluation, diagnostic and treatment process in a more detailed manner. For example, a more detailed product could have been created for each part of the process in order to be able to include much more information in the Fotonovelas. Again, this was not completed due to time constraints on product development.

Future Directions

Once the Fotonovela was created it would be used as a tool to be handed out by professionals such as speech language pathologists or other therapists to determine its effectiveness. Professionals could then rate the product as helpful or not helpful in providing important information to Spanish speaking families. In order to appropriately determine the effectiveness of these products, they must be field-tested. Families and professionals would be asked to rate the product to determine if the purpose of the product was accomplished. After the data collection, the effectiveness of the novella could be determined. The next step would be polishing the Fotonovela and possibly publish it as an effective bilingual tool. The creation of other companion Fotonovelas including information about the process that takes place after early intervention services could also be a future endeavor for this study.

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For copies of the Fotonovellas created for this project. Please contact Valeria Font Zorrilla at valfontzor@gmail.com.

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