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What We Can't Understand: The Non-Verbal Verbal Communication

Among Autistic Children

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Submitted in Partial Fulfillment of the
Requirements for the Degree in
Bachelors of Arts in Communications and Media Studies
School of Arts, Humanities and Social Sciences
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This thesis, written under the direction of the candidate's thesis advisor and approved by the Chair of the undergraduate program, has been presented to and accepted by the Faculty of the Department of Communications and Media Studies in partial fulfillment of the requirements for the degree of Bachelor of Arts. The content and research methodologies presented in this work represent the work of the candidate alone.

Dedication

To my mom, dad, and big brother. I couldn't have done this without your constant love and support. Love you more. And to all the families of children and adults with autism, your positivity and outlook has truly inspired the way this thesis was written. Thank you to everyone who has supported me and provided me with the necessities to succeed.

Abstract

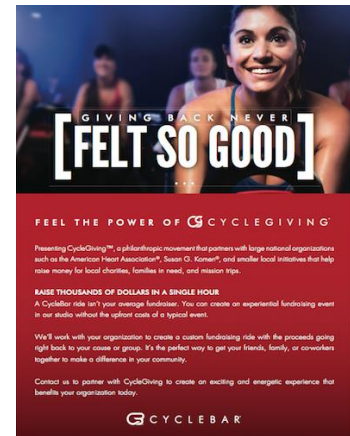
This project is about children on the Autism Spectrum Disorder and the tools they use to communicate with others. I touch on the ways parents can help their children at home and how they can assist their child to talk even if they are told they will never do so. Discussed in the paper are the various methods of communication including PECS, the QWERTY keyboard, and mobile applications. These can be used on an iPad, iPhone, smartphone etc. The nutritional benefit of some foods for children with autism is also a contributing factor of how they act. Eating foods such as gluten, casein, and dairy have shown to bring about an increase in outbursts for a child with autism. I review some of the methods to boost a child's communication skill at a young age and go over methods of communication that you can do at home without purchasing an app or using a keyboard, or picture exchange communication system. Some parents decide to go a different route altogether and decide to use homeopathic methods of helping their child succeed. It is essentially the family's decision of what works best for their child. I have found it to be a lot of trial and error deciding what method to use with an autistic child. It really is what is best for your family and most importantly what is best for their child.

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Appendix I

As part of my thesis project I decided to organize a charity ride with Cyclebar in Novato, California. Cyclebar is a fairly new studio in our area and I decided to utilize this. A majority of the company's initiative is to give back to the community by hosting these rides to people who are interested in raising money, all while exercising and getting some benefit to those who donate. I wanted a way to bring the community together while raising money for a great cause. I thought bringing together a community to form as one could have a positive impact on Marin county as well as raise the money and bring awareness to an important topic. The rate at which autism has risen in the past ten years is uncanny and there needs to be far more awareness on why this rate is growing. I did the research on who the proceeds would go to and knew I wanted something with the research of autism, and I soon found the Autism Research Foundation located in Boston, Massachusetts. The reason I chose The Autism Research foundation was because of the rate at which autism has spiked in the last decade. I knew if I wanted to get to the source of that I would have had to raise money for a cause that does just that. I posted on my social media to promote the event, along with the social media of some of my friends and family members. We ended up getting a huge turnout of 22 people along with many generous donations. We raised over 500 dollars in a one-hour cycling class. I was very pleased with the results of this and can't wait to get other individuals involved in giving back to our community. Overall, the cycle ride was a lot of work but if I could go back I wouldn't do it any other way. It was stressful at first to get everything done and have enough people available to



ride that specific day but it was worth it. Once I figured out how to market myself through social media and word of mouth it became a lot easier to get it done. I can definitely see myself doing another ride or fundraiser in the near future.

Introduction

Autism affects 1 in 68 children in the United States. This rate has jumped 30 percent since 2014 and remains one of the fastest-growing developmental disorders in the nation today (Autism Speaks). Parents of autistic children are often told by medical professionals that if their child of communication the odds are not completely against them.

There are several types of autism that determine how well one's child will be able to communicate. These types of autism include Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder. Autistic Disorder usually includes language delays, social challenges as well as communication challenges, and unfamiliar interests or manners. The next level is known as Asperger's syndrome. Those with Asperger's have mild symptoms rather than those of the Autistic Disorder; they might face some social challenges and unusual behaviors but problems with language or intellectual disabilities are scarce. The third and final level of autism includes Pervasive Developmental Disorder or (PDD). This level includes those who are in the middle of Autistic Disorder and Asperger's Syndrome; they meet some criteria for both. They usually have milder symptoms for autistic disorder and some of these symptoms could cause social and communication challenges (ASWS.org 1).

This research is important for the simplicity of the awareness on my topic. People need to understand that children with disabilities such as autism may be faced with feeling ashamed or may begin to face social problems with their peers. This is due to their equals not understanding who they are and why they do the things they do. An inability to communicate with others certainly does not make it any easier with these

social interactions. Throughout this research I hope to accomplish getting this awareness out and to get a better understanding of autism myself. Before this I thought I was an expert on the topic of autism but soon realized there was still so much to learn. I hope that through this research other people will find that there is so much more to this neurological disease than we could ever imagine, and that it will encourage others to research more for themselves to become more aware on the topic.

Research Questions:

- ◆ What are the different methods non-verbal children use to communicate?
- ◆ How are these methods helping non-verbal children communicate?
- ◆ What is autism? How can we understand this?
- ◆ How are mobile apps turning the way for nonverbal children?
- ◆ Homeopathic approaches to assisting with autism?
- ◆ How do food effect children with autism?

Understanding Autism

To understand how difficult it is being a child with autism – being a child who cannot communicate with others in the way everyone else around them can – we must break down what autism is in general. “Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors” (What is Autism?, 2013). Children with autism are often diagnosed at an early age because their atypical social

engagement and repetitive behaviors are easily identifiable. For example, an autistic child may actively pursue isolation when social opportunities are available or tirelessly repeat an activity, such as lining up toys, or an action, such as rocking back and forth. In addition to not being able to fully interact with other children or peers, these children often struggle with verbal communication. This often results in children with autism feeling alone, segregated and generally confused by the situations they have absolutely no control over.

Naoki Higashida, a now 23-year-old non-verbal autistic man, wrote a book describing this pain he endures daily. “Because I’m barely able to hold a conversation, fixing what’s gone wrong is beyond my powers. Every time this happens, I end up hating myself for being so useless and clamming up” (Higashida, 2013, p.19). Communication is a major part of everyday life. Whether it is signaling a proper hello to friends, or presenting a report in front of a classroom full of peers, communicating is a vital part of the way humans live. Unfortunately, a lot of the communication that comes naturally to typical children, proves to be extremely difficult for autistic children. The brains of autistic children are programmed differently. This is not to say the difference is a negative one, but the difference can make for highly challenging experiences with verbal communication.

The Importance of Nutrition

There are numerous ways through which different factors in everyday life can affect a child with autism and make some of their behaviors worse. One of those factors

includes the food they consume. Many families choose to change their child's diet altogether and become gluten free, dairy free and sometimes-even casein free. Many studies have been conducted testing this theory out. Essentially parents will remove gluten and casein from their child's diet e.g. wheat, barley, rye, oats, rice and all dairy products. "Gluten and casein diets are exogenous source of opioid like peptides. The basic purpose of eliminating these foods is to stop opioid peptides from entering the brain in excessive amount. So that these peptides cannot affect brain functioning and see how the symptoms of autism respond to the deprivation of opioid peptides." (Saeed et al, p. 1) These peptides can openly affect brain development "Both endogenous and exogenous peptide molecules affect brain processing. Exogenous peptides are derived from food sources like gluten and casein." (Saeed et al, p. 1) Eliminating these foods require no training for parents, only implementation of the elimination of these foods. The results showed that the contributors of the gluten-free diet resulted in advances of numerous behavioral measures. (Saeed et al, p. 2) Utilizing these small changes, a child's diet can help the overall wellbeing of someone with autism.

Picture Exchange Communication System

As humans seem to advance at a more powerful rate these days, so does technology, providing non-verbal children with a voice that needs to be heard. By creating this voice for them, we as researchers can understand what they are thinking instead of going on assumptions. "The Picture Exchange Communication System (PECS) is a popular augmentative communication system frequently used with 'nonverbal' children with autism. Several studies suggested that PECS could represent an effective

tool for promoting improvement of several social–communicative skills” (Lerna et al, 2014, p.1). Creating various picture templates that autistic children can use to communicate with others can increase communication skills they might not have acquired otherwise. Throughout these phases children are introduced to a communication book with symbols, such as a banana, a coloring book, or whatever they might want. The child is then told to take a symbol from this book; say a banana, and walk a certain distance to the communication partner to request what it is they want. Creating a physical distance between the child and communication partner helps the child not only communicate with others but to work for the item that they wish to acquire. (Reszka & Watson, 2010, p. 2) This distance is key in the communication of the child with autism. Many children desire something but are not willing to work for it and creating this distance is important to note to the child that, just like any other child, they will not just be handed something. It is important to treat those with autism as “normal” as you possibly can, because one day they will have to live in the real world and deal with real life events. Preparing them for anything that life may throw at them will only benefit them in the long run. This distance between the communication partner shows how far the child is willing to go for what they want. This teaches the child the reality of what people have to go through to get what they desire in life.

The Alphabet Grid

Another way to communicate is using a system known as an alphabet grid. This is similar to a keyboard that most of us use daily, but instead the non-verbal child points to the desired letter and a scribe and/or instructor writes down what the child is trying to say

from there. Naoki Higashida wrote several books using this method at the young age of 13; although he was highly intelligent in regards to the Autistic spectrum, “his autism was still severe enough to make spoken communication pretty much impossible, even now” (Higashida 2013, p. 6). This process has been described thusly: “A Japanese alphabet grid is a table of the basic forty Japanese hiragana letters, and its English counterpart is a copy of the QWERTY key-board, drawn onto a card and laminated. Naoki communicates by pointing to the letters on these grids to spell out whole words, which a helper at his side then transcribes. These words build up into sentences, paragraphs and even entire books” (Higashida 2013, p. XIII). That’s right – letter-by-letter, period-by-period, apostrophe-by-apostrophe, a scribe is there providing constant assistance, and the child is creating these same phrases letter by letter. The process is drawn out and can be somewhat of a test for the patience of both parties involved.

Mobile Applications

The final and most advanced way has made its way recently into my knowledge of autism by a boy named Dillan Marmache, who has completely changed the way I look at children who are nonverbal. Marmache is a fourteen-year-old boy living in Los Angeles, California, and has grown up struggling to find his voice, by simply not being able to create one for himself. He first became an internet sensation when he presented a speech at his middle school graduation in 2014, but now Dillan is sweeping the nation once again with a new Apple marketing campaign released just days ago. Marmache is now the face and hope for hundreds of non-verbal autistic children struggling with literally not having a voice. Non-verbal children are now able to type out their thoughts

and feelings and project them through special software, similar to Siri's voice. By this method Marmache was able to get up in front of his entire school and speak his mind, something he has never been able to do. Marmache explains this expression as such “Having a voice has changed everything in my life. No more isolation. I can finally speak with the people who love me. I can say what I think and let them know I love them too” (Non-Verbal Teen with Autism Gives Inspiring Graduation Speech (2014)).

Most of the Autism community have seen the recent Apple campaign with the non-verbal autistic teen being able to find his voice through the use of his Apple iPad. Studies have been conducted whether or not these products allow non-verbal children to learn from what they are using, like the PEC system or the alphabet grid. King et al (2014) wrote:

“Some characteristics of technology are suggested to be compatible with the characteristics of ASD. For example, children with ASD prefer electronic media, may respond better to the game-like nature of technology, the visual strengths of children with ASD are utilized with technology, and the computer- generated speech associated with technology may be beneficial for children with ASD (Schlosser and Blischak, 2001).” (p.1)

The choice of which communication mechanism autistic children like best really depends on their likes or dislikes of technology. Those who do best with technology will thrive with these apps, and those who don't will continue to use the other two communication tools. These apps can be used by an iPad, Macbook, or iPhone. This

technology works through a speech-generator that voices what the nonverbal child types on the keyboard they are given. Similar to texting, or using Siri ,children are now able to voice their thoughts and opinions. Most importantly these children are now able to speak up in a classroom and participate, thus creating a positive learning environment for the non-verbal children who may be eager to learn. (King, et al 2014 p.2) Depending on the non-verbal child's preference the apps on the iPad can be life changing because it is versatile. Because the function of an iPad is mainly through applications, the possibilities are endless when it comes to the schooling of children (King et al, 2014, p.4). There is an app for almost anything out there, which diversifies the possibilities for any population of people including non-verbal autistic kids. These apps on mobile devices are changing the lives of children with autism simply because they finally have a voice, a voice to say what they really mean, a declaration to finally tell their parents that they love them.

Methods to Boost a Child's Speech

Along with these devices and visuals there are other ways at home that families of the non-verbal child can help them in communicating and even get them to begin to talk minimally with them. The first is through play and interaction. Children tend to learn through playing games, singing and reciting nursery rhymes; these are just a few of the ways to communicate with your non-verbal child. During these important interactions keeping an even eye level with your child is important for their development.

The next way to help your child communicate is through imitation through sound, gestures etc. If your child expresses positive behavior, be sure to imitate that as well. While the child is playing with a toy, imitate what he/she is doing with that toy. Focusing

on the non-verbal communication that their child shows is the next important aspect.

Lauren Elder Assistant director of Autism Speaks states:

“Encourage your child by modeling and responding these behaviors.

Exaggerate your gestures. Use both your body and your voice when communicating – for example, by extending your hand to point when you say ‘look’ and nodding your head when you say ‘yes.’ Use gestures that are easy for the child to imitate. Examples include clapping, opening hands, reaching out arms, etc. Respond to the child’s gestures: When she looks at or points to a toy, hand it to her or take the cue for *you* to play with it.

Similarly, point to a toy you want before picking it up.” (Autism Speaks 1)

The next method is to simplify the parent’s language with their child. This makes it easier for the child to copy what you are trying to say and makes it easier for the child to understand what you are trying to communicate with them.

Following what the child is doing is also important. If they pick up a car you can pick up another one and let them know this is a “car” or tell them what color car they are playing with. Repeating these behaviors can strike a realization with your child that is in fact a “car” they are playing with. Finally, leave space for your child to communicate with you. Don’t interrupt them, correct them, or get frustrated with your child if they don’t respond to you immediately after your question. When asking questions to the child, be sure to give them longer than a few seconds to respond; patience is the key to getting the child respond to you even if its minimal response (What is Autism, 1). These crucial developmental exercises could get a child past the age of four to talk minimally, giving families even more hope for their child’s future.

Methods of Communication at Home

If these methods at home don't work when trying to get your child to communicate the next step is accepting the situation and realizing they may never speak. There are many approaches beyond mobile applications and other resources. A few of these include keeping the child in the loop and continuing to discuss what's going on in the world, in your personal lives as well in their lives. Don't ignore the situation but instead embrace it, continuing to discuss what is going on in their daily lives. Teaching the child to clap or make some sort of hand gesture to respond "yes" or "no" to a situation can also be extremely helpful in the communication process. Putting stickers or some sort of emblem on your forehead can remind your child to always keep eye contact with those they are attempting to communicate with, or just having that constant reminder to use eye contact when you are talking.

A parent can make flashcards with some of their favorite objects, or things they use on a daily basis, and encourage your child to point to a desired item (similar to the PECs but more geared towards your child's favorite things). Carry a "surprise card" for unplanned instances that a child may not be ready for. Write on the card "surprise we are going to the zoo!" or whatever the child's favorite location may be to avoid a potential breakdown. Sign language is also an important tool that many people may want to consider, depending on your child's development. If the family and child can learn sign language, this could be another easy form to communicate with them. Create a personal portfolio for your child describing who they are, interests, likes and dislikes. Making a portfolio such as this can make it easier for a child to introduce themselves to other classmates, teachers, or friends.

A Homeopathic Approach

Mother and author Connie Wisesan describes what her autistic son was like before she decided to try homeopathic methods, “Nothing was helping, not really. Not even the special schools and behavior modification. It still felt like a part of him was missing -- a part of his soul. When I was with him he felt like an empty shell of a body. He had a very healthy body, but empty” (Wisesan 90). After struggling with this for some time, Wisesan knew there had to be something more out there that could bring this light back to her child. Frustrated and willing to do almost anything, Wisesan decided to hire a shaman to come into her home, little did she know her son’s life would be changed eternally. The shaman listened to her story and began her practices. She drummed, lit candles, called in animals, and told Wisesan to picture her son in front of her. “I started to feel a strange buzzing in my body. I felt all tingly and cold and my right hand started to levitate. It started to slowly rise on its own. Like a puppet’s hand on a string. Well this was new” (Wisesan 93). Wisesan began to see a white orb in her distance and found her hand moving towards the light, “And when I checked in with it, it said it wanted to be placed in Alex. So I reached out and took it into my hand...and placed the orb in the picture of Alex before me” (Wisesan 94). For the next two hours the shaman and Wisesan spoke, the shaman answering as many of her questions as possible. The shaman told her that Wisesan had a gift for homeopathic healing and this would someday be her destiny, and that shaman was not wrong. Her son got off the bus that same day and to Wisesan’s surprise her son was a completely different person. Wrote Wisesan: “I will never forget the look on your face as the school bus door opened and you came down the stairs. Alex

my son, you were there. You were in your body. I felt you again. You looked at me and smiled, really smiled. You rushed into my arms and said: “ma, ma, ma, ma!” You were so chatty. My soul felt your soul. You were back and I was a believer” (2015, 95).

Through this homeopathic method, Wiseman’s son was revived and his soul was essentially cured. To this day he still has the spirit, intelligence and love of a boy who is not severely autistic, giving Wiseman so much hope for his future.

Conclusion

Mobile applications along with the old school ways to help non-verbal autistic children communicate are all shaping the way these children are turning out. With the constant progress of technology autistic children are becoming more advanced in terms of communication. Many parents no longer have to worry about what their child is going to become because of their disability. By being able to have so many options to communicate better with your peers, children with autism and their families now have an option to help find the right method of communication. Whether parents start at home or they choose a more natural, homeopathic method there are options for families of autistic children. These apps, along with the help of peers and instructors are giving children a voice again, a voice they might not have had ten years ago. Giving these children an opportunity to have a voice again can shape the way they live their lives.

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