

Kirsten Temple

17 April 2016

COMP211

Final Draft

### Autism: Inclusive Diagnosis vs. Exclusive Treatment

Has your mood ever been disrupted by a sudden change in your schedule? Are loud sounds unpleasant to you? Have you ever felt overwhelmed by a social setting? Do you avoid talking about yourself? Are you a picky eater? If you answered yes to any of these questions, you could be placed somewhere on the autistic spectrum. Although most people do not have what is medically diagnosed as autism, the actual spectrum includes pervasive developmental disorders of all intensities. Technically speaking, this means that in some way every person can fall somewhere on the autism spectrum. The previous test demonstrates just how inclusive the autism spectrum has become over the last few decades. It is no surprise, then, that 1 in 68 children are diagnosed with an autism spectrum disorder (ASD) every year (Autism Speaks, 2015). Because so many children are being diagnosed with ASD, more children are seeking treatment than ever before. However, a conflict arises as both the definition and diagnosis of ASD continue to broaden but treatment plans remains the same. Each case of ASD is different, so each child's treatment should be tailored exclusively to their needs. One way to modify treatment in this way would be to focus on building relationships with autistic children. This type of treatment allows the parent/therapist to get to know each child's unique gifts and challenges as well as teaching the child social skills. Many people with ASD often mistakenly view their situation as hopeless

and their contribution to society as minimal, but this hands-on treatment perspective can help to redefine autism as an “ability” to see the world uniquely rather than a disability (King, 2008). Although the recent inclusive diagnosis of autism spectrum disorder has made an exclusive treatment approach challenging, it is still essential that parents and therapists attempt to build personal and meaningful relationships with autistic children that facilitate the development of each individual’s unique characteristics in order to help them contribute to society.

### **What is autism spectrum disorder?**

There are five Autism Spectrum Disorders, also referred to as Pervasive Developmental Disorders (PDD). These five include Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS), Rett Syndrome, Childhood Disintegrative Disorder, Asperger Syndrome, and Autism or Autistic Disorder (Autism Science Foundation, 2016). While these are all different diagnoses, these five disorders all have similar manifestations in a person’s life and similar treatment approaches; this classifies them all under the umbrella of PDD. Autism is one of these developmental disorders that specifically impairs a person’s ability to communicate and interact with others. A person with autism has a functioning brain capable of intelligence, but lacks the skills to communicate normally. Children can be diagnosed as young as six or seven months and most are diagnosed before the age of three. Interestingly, it is reported that boys are four times more likely to have autism than girls (Autism Science Foundation, 2016). These numbers appear to alter the understanding of ASD as an inclusive disorder; however, there are a plethora of debates on how accurate these statistics really are. Some say that boys and girls simply have different social tendencies which makes their autism more or less apparent. About girls, Robyn Young (2015), an associate psychology professor at Flinders University in Australia, says, "They

often develop a way to camouflage their symptoms. Also they tend to obsess over friendships and can develop them, or one or two close and like-minded allies." She goes on to argue that boys are more likely to isolate themselves from their parents and classmates. Because of these differences, autism can be more difficult to diagnose in girls than it is in boys. This argument goes on to say that there is probably an equal number of girls with autism who have just not been formally diagnosed (Sarris, 2015). ASD, then, remains as inclusive as ever.

Often, people with autism have unique interests and atypical approaches to learning. Some physical indicators of autism include: avoidance of social settings, delayed speech, resistance to change, poor eye contact, fixation on one task, difficulty paying attention, repetitive behaviors such as hand flapping, and sometimes aggression (Holland, 2003 pg. 39). Each case of ASD manifests itself uniquely. This diagnosis lasts a lifetime but therapy can make a difference in minimizing these symptoms. Scientists do not all agree on what causes autism, but the most recent proposition has to do with a myriad of genetic components. There are several studies in which scientists determined if one identical twin has autism, it is 80-90% likely that the other identical twin will have autism. However, with non-identical twins, this chance decreases dramatically to 3-10%. This second statistic is the same as a likelihood that siblings would both be affected as well. This study points to genetics as the main cause for ASD (Autism Science Foundation, 2016). While there has been much controversy discussing whether or not environmental factors play into an autism diagnosis, most researchers agree that this connection, if present, is minimal (Flippin & Watson, 2015). There is no known cure for autism at the present, but it is important for those treating autistic children and adults to have an optimistic

attitude towards the quality of life attainable for someone with ASD, because research continues to advance every day.

### **Has ASD become a bigger problem recently?**

Over the last few years, there has been a steady increase in the number of autistic cases diagnosed. In 2000, 1 in 166 children were diagnosed with autism; by 2014, this diagnosis became much more prevalent with a ratio of 1 in 68 children diagnosed (2015, Autism Speaks). While some attribute vaccines and other environmental factors to this growth, research shows the cause can be found elsewhere. Clinical neurologist and professor Steven Novella (2008) says, "...the rise in incidence is mostly or completely an artifact of increased surveillance and broadening of the definition of autism." (Novella, 2008). By observing the increase of people with autism as simply a change in clinical definition, there is no need for a panic concerning environmental factors causing any "autism epidemic." There is, however, an issue concerning treatment for ASD due to this change in definition. Due to what is known as diagnostic substitution, what would have previously been diagnosed as speech impediments, relational difficulties, or other disabilities are now classified under one umbrella- autism spectrum disorder. While one child may need encouragement in speech or mathematics, another may excel in both but struggle with motor skills. It is obvious, then, that coming up with a comprehensive treatment plan for children with ASD is a challenge. However, it is not necessary to have one inclusive treatment plan. It is more beneficial to have many tools that can be tailored to treating each child's autism exclusively. It is tempting to ignore the wide range of ASD in order to come up with a simple treatment, but this is not realistic or helpful to the children living with autism

today. Instead, each case of ASD should be reviewed carefully, and a unique plan should be put into place in order to best help each child.

**Is it really possible to tailor every treatment approach to each child's specific symptoms?**

It is possible to make a plan for treatment with one child's case exclusively in mind. It all starts with the family. The popular saying, "it takes a village to raise a child" is no less true when raising an autistic child- it is even more essential (Hillman & Gruber, 2013). While the task of raising a child who has been diagnosed with a series of social disabilities may appear daunting, there are countless testimonies of parents and siblings whose lives have been changed for the better by their autistic family members. Genetta Adair (2010), mother and author of "How Autism Changed My Life," says, "If I could start again and choose whether to have a child with autism, I wouldn't change a thing (Adair, 2010)." There are also multiple accounts of autistic children's lives being completely transformed by a dedicated loved one. Benjamin Tarasewicz (2015) comments on his mother's involvement in his life by saying, "No matter how hard things got at times, she always aimed for the stars. She always believed in me and believed in my potential to grow. That's one of the biggest gifts and greatest kindnesses you can extend to someone with autism. (Tarasewicz, 2015)." In the case of Chris Varney (2013), a young boy with ASD, his mother, Lisa, changed his life and potentially the lives of many others. When Chris was diagnosed with autism, Lisa refused to accept that her son's life would be defined by his autistic tendencies. She instilled in her son the value of his uniqueness while teaching him to persevere in all situations. Chris now speaks publicly on how she set up a network of people to encourage him with an "I CAN" attitude as opposed to one of defeat. He describes the value of her unconditional love and support despite many social and developmental obstacles saying, "I

am living and breathing her rethink (Varney, 2013)." Chris's situation was not unlike that of many people with autism, and with the guidance of his family and friends, today he is able to use his uniqueness to teach others how they can make a world of difference just by changing their perspective and refusing to give up on autistic people.

**Does a perspective really make that much of a difference to treatment?**

Chris's story brings about a new question: how much of a difference do treatment perspectives really make? One major component that has changed as more research has been done on autism is the perspective which therapists, parents, and anyone else regularly working with autistic children adopt. Florence Milnes Kozak's (1986) book, *Autistic Children: A Working Diary*, demonstrates this well. Over the course of two decades, Kozak documented her work with autistic children. When she began, in the mid 1980's, the cause of autism was commonly attributed to emotional tragedies at a young age- specifically parental neglect and lack of social stimulation. Naturally, Kozak adopted this perspective when working with an autistic five year old, Karen, and her parents. Because ASD is such a broadly defined disorder, Kozak struggled to determine where to start treatment for Karen. Eventually, she assumed that since Karen's unusual behaviors were due to what she believed were her parents' failings, much of her treatment had to do with eliminating negative commands from her parent's vocabulary and providing Karen with an abundance of compliments. Although these things often seemed to make a difference for Karen, they began to serve as hindrances to Karen's growth as she began to expect people to coddle her all the time. By using this treatment plan, they were ultimately protecting her from the real world and creating a false sense of reality in Karen's mind (1986, Kozak. pg. 77). However, as Kozak's research and experience grew, she began to realize how

flawed it is so presume autism is anyone's "fault"- especially the fault of the people who love the child the most. About ten years after her time with Karen, Kozak spent a few years working in a group home for autistic boys. Here, her reasoning, and the reasoning that is commonly agreed upon today, was that autism is actually a central nervous system disease. Because of this change, parents were no longer ashamed to have their child diagnosed with autism. Instead, they were encouraged to do so in order to learn how best to help their autistic children. This perspective opened up an entirely new treatment approach that is evident in how Kozak focused more on teaching the boys how to make the most of their lives instead of trying to protect them from any emotional stimuli that may set them off. Through this approach, the boys were able to develop their own uniqueness while gaining valuable skills that would equip them for the rest of their lives. So, by simply altering her perspective, Kozak's treatment plan for each child was dramatically changed for the better.

### **Is it realistic to be hopeful about finding a cure for ASD?**

Although there are myriads of ideas for managing symptoms of autism to help autistic children become adults who can contribute positively to society, there is no known cure for ASD. However, a key component to treating autism is hope. Research has never stopped when it comes to searching for a cure. One of the latest ideas revolves around combining the different fields of research in hope of discovering something new about ASD. Although this seems to be a way to make treatment for individuals more inclusive, the result of this combination is actually the opposite. Those supporting this idea of coherence point out how many different professionals study and treat autism due to the extensive number of theories on the causes of autism, why it is so prevalent, and how to treat it. Professionals in developmental and biological psychology,

ethology, comparative cognition, neuroscience, genetics, child psychiatry, education, speech therapy, occupational therapy, and myriads of other fields all have research perspectives regarding ASD (2008, McGregor & Nunez & Cebula & Gomez). By working to combine the research from their fields, researchers can offer thousands of ideas for how to exclusively treat autistic people. Essentially, this coherent approach would say, while the neuroscientist's approach may work for one child, the child psychiatrist's may be more effective for another. This idea of finding coherence in autism research is only one of the methods providing hope to those searching for treatment options for their unique case of ASD.

Hope can also be found elsewhere. Autism does not have to be viewed as a "disability" by those who are on the spectrum or by those who love and work with autistic children. Instead, it can be seen as the ability to live uniquely. In her talk, "How autism freed me to be myself," fifteen year old Rosie King (2014) said, "I haven't told many people this, but in my head, I've got thousands of secret worlds all going on all at the same time. I am also autistic." King demonstrates how unique her perspective of the world is with just this one simple statement. There is no other person on this earth who will have overcome the things she has overcome or be able to delight in the worlds she has created in her mind. King stresses how important it is for people who do not have autism to keep an open mind- not just when it comes to autistic people! She says that some of her "abilities" thanks to her autism are her vivid imagination and her lack of interest in what others think of her. Although many view these things as negative aspects of ASD, King has redefined them as positive. A powerful illustration that she uses has to do with putting people into a box labeled "normal." While addressing her disregard for this "box" she says, "I wouldn't be here, I wouldn't have achieved half the things that I have now." Taking this



idea of “normal” one step further, it is important to understand what the word actually means. Normal today means whatever the majority is doing. Even if the action is totally bizarre, if everyone is participating, that action becomes “normal.” King challenges this notion with these powerful statements: “Why are people pouring their brilliant individual light into a mold? People are so afraid of variety that they try and force everyone, even when people who don’t want to or can’t, to become normal.” As King says, why are we not equipping young people today to be extraordinary and to step outside of the box? (King, 2014).

Each person, whether they are on the autism spectrum or not, has unique talents. What good would it do if everyone stifled their gifts in order to fit into a mold of normalcy that means nothing? While this principle can be applied to all people, it is especially true with regards to autism. Many people with autism, especially those with Asperger’s Syndrome, excel in one or more specific areas of life. Some are brilliant mathematicians while others are gifted in arts or logic; there is no limit to the unique abilities many autistic people have. Therefore, there should be no limit to what an autistic person can accomplish when they discard social stigmas and live their lives without fear of the “normal box.” Rosie King’s testimony is an incredible example of this truth.

### **What are some practical ways to help autistic children learn and grow?**

Despite the lack of a cure, there are many ways to help autistic children live happy and accomplished lives. In their book *1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorder*, mothers Ellen Notbohm and Veronica Zysk (2004) suggest a multitude of ways to teach autistic children simple social behaviors. Often, an autistic child’s

biggest struggle is picking up on and processing social cues. Notbohm and Zysk propose conditioning the child to acknowledge certain hand signals as cues to do things like: stop chewing with an open mouth, stop monopolizing a conversation, or stop interrupting. These cues are good ways to teach autistic children manners. However, it is important to remember that each child will learn differently, so while this approach may work for one child, it might be ineffective for another. For a child who might learn differently, this approach may work better: encourage the child's good behavior- no matter how insignificant the act (2004, Notbohm & Zysk pg 63). This type of reinforcement puts the focus on the child's positive actions as opposed to only focusing on their negative responses through punishment. In many cases of autism, things that a child would typically learn on their own need to be taught and repeated...and repeated again. From simply looking at only these two basic suggestions, it is obvious how different treatment approaches for different cases of autism can be. It often takes a series of trial and error to find what works best for one child, and the same series of trials will most likely have completely different results with a second child. The importance of exclusive treatment becomes more apparent with each new child diagnosed with ASD.

Overall, treating a child with autism should look like a relationship. There used to be a common misconception that autistic children were not capable of forming relationships. This idea set autism research back years but has been invalidated today. Florence Kozak (1986) explained that in order to truly help autistic children (in her case, the six boys in the group home) it was essential that she get to know each child's strengths, challenges, and personalities: "We saw each boy as a unique personality, each with his own special emotional needs (Kozak, 1986, pg. 85)." Kozak also stresses the importance of an intimate relationship when she speaks of how

much faster Karen progressed once she established a strong bond with her (1986, Kozak. Pg. 77). Kozak's determination to treat Karen in a one-on-one setting with activities specifically tailored to Karen's attitude, actions, and speech for that day made a massive difference in Karen's overall behavior. Through Kozak's research it is evident that this intimate, exclusive approach creates an easier atmosphere for autistic children to learn. Not only does this exclusive approach help them overcome their autistic tendencies, but it teaches the children, and others, that it is very possible for them to form meaningful relationships as well. This idea is not specific to autism; in fact, it should not be a foreign concept at all. In order to help anyone learn, one must first establish a foundation of trust with that person- they must build a relationship. There is no reason why autistic children cannot be included in this notion of friendship.

### **What kind of difference does friendship make for an autistic child?**

For almost anyone, a friend can change a bleak afternoon into a joyous one. For Benjamin Tarasewicz (2015), a high-schooler with autism, one friend changed his entire high school experience from being a time of loneliness to a time of thriving. Benjamin said, "I've experienced how unkind people can be when they don't understand something- teasing and bullying comes to mind. I've also seen the changes that happen when people learn about each other. (Tarasewicz, 2015)." Benjamin hits on a very important point: fear of the unknown. Often, when something is new or different, people find reasons to believe it is bad or inferior. In this case, people at school who did not understand autism found that the best way to compensate for their fear was to bully Benjamin. Although these incidents were unpleasant, they facilitated a moment of openness between Benjamin, his teachers, and his classmates. By explaining autism to his classmates, with the help of his parents and teachers, he was able to break down social

barriers at his school. His openness caused others to be honest with him, and he was able to make several lasting friendships. One of Benjamin's friends even invited him to prom and to an after-prom party in what Benjamin describes as a "great kindness (2015, Tarasewicz)." These normal activities are often taken for granted, but to Benjamin, they were some of the best experiences of his life. Although he was noticeably different from the other kids, Benjamin was a part of their world that night; he was finally included. Benjamin continues to break stereotypes, and now he is regarded at this school as a role model- a massive turnaround from the previously bullied kid!

Unfortunately, not every social situation has a Benjamin to teach others about autism. By typing "autistic people are" into Google, it is surprising to find one of the search suggestions to be "demons" (King, 2014). This is only one example of how much negative stereotyping surrounds a diagnosis of autism. Unfortunately, a fear of the unknown often facilitates these stereotypes. Ideas that autistic children are unfriendly or don't want friends harm these children's ability to make friends. Mother and author of *The Dragons of Autism*, Olga Holland (2003), says that two people are real friends if:

1. They witness the unfolding of each other's lives.
2. They mirror each other's participation in life.
3. They provide support and help for each other as needed.
4. They participate in an unwritten nondisclosure pact.
5. They share their thoughts, their dreams, and their hopes. (Holland, 2003, pg. 155)"

This kind of friendship is an important part of any person's social development. It is typically not easy for anyone to find friends that could meet this criteria. For an autistic child, it is even more of a challenge. Many schools offer afternoon socialization programs in which

children who struggle developmentally spend one or two hours a week with some typical children. However, this type of environment does not often facilitate genuine friendships but instead forces all the children to often participate in activities they would rather not be doing. In the end, autistic children often get overlooked and do not have many real friends. These situations often allow stereotypes to thrive, and sometimes eventually creep into the child's understanding of him/herself. Holland expresses this fear when she says, "Would it be surprising if somewhere deep, subconsciously, a child may form a fear of his own fading nature, of his unimportance, of a lack of purpose in his life? (Holland, 2003, pg. 157)." As well as skewing the child's understanding of him/herself, these harmful stereotypes also misinform the public and take the focus off of what is really important- helping children with autism. This poses a challenge to anyone who does not have autism: seek those with autism out! As Benjamin's friend did by inviting him to prom, you can extend kindness in the form of friendship to someone with autism as well. While every situation is different, it is likely that by being a friend to someone else, you will also gain a friend.

### **Conclusion**

Although a diagnosis of autism spectrum disorder has become more common, it is still possible for treatment to be effective. In fact, treatment plans should be even more exclusive than ever before in order to compensate for diagnostic substitution. If treatment is not approached exclusively, those struggling in one area will receive treatment meant for someone struggling in a totally different area. The best way to approach treatment exclusively is to build a meaningful relationship between parent/child or therapist/patient. There is no better way to learn how a specific autistic child thinks and learns than to get to know him/her on a deep personal level. By

establishing this kind of relationship, the child not only learns that he/she is capable of relating to others, but they are encouraged to do so in other settings as well. Having a relationship like this provides the autistic child with a safe place to try out new social skills without fear of failure or embarrassment. This type of relational treatment serves to benefit not only the autistic child, but it gifts the parent/therapist with the ability to understand an entirely new perspective of the world- from the eyes of an autistic child. By tailoring treatment exclusively to one autistic child at a time, the inclusivity of the autism spectrum ceases to matter. The autism spectrum can be redefined a thousand times, but the individual's growth will not be hindered because their treatment is not centered on their diagnosis; it is focused on building and learning through relationships.

## References

- Adair, G. (2010). How Autism Changed My Life. Retrieved from [http://nowwhat.cog7.org/Articles/Home-Family/Children/How\\_Autism\\_Changed\\_My\\_Life.html](http://nowwhat.cog7.org/Articles/Home-Family/Children/How_Autism_Changed_My_Life.html)
- Autism Science Foundation. (2016) "What is Autism?" Retrieved from: <http://autismsciencefoundation.org/what-is-autism/>
- Autism Speaks. (2015, January 5). "Can Rise in Autism Be Explained By Broadened Diagnosis?" *Autism Speaks*. N.p. Retrieved from: <https://www.autismspeaks.org/science/science-news/can-rise-autism-be-explained-broadened-diagnosis>
- Adair, G. (2010). How Autism Changed My Life. Retrieved from [http://nowwhat.cog7.org/Articles/Home-Family/Children/How\\_Autism\\_Changed\\_My\\_Life.html](http://nowwhat.cog7.org/Articles/Home-Family/Children/How_Autism_Changed_My_Life.html)
- Flippin, M., & Watson, L. R. (2015). Fathers' and Mothers' Verbal Responsiveness and the Language Skills of Young Children With Autism Spectrum Disorder. *American Journal Of Speech-Language Pathology*, 24(3), 400-410 11p.
- Hillman, J., & Gruber E. (2013). It takes a village: Redefining kin, extended family, and other social networks in the treatment of childhood autism. In *Understanding Autism Spectrum Disorder: Current Research Aspects* (pp. 15-28). Retrieved from <https://milligan.idm.oclc.org/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=541181&site=eds-live&scope=site>

Holland, O. (2003). *The Dragons of Autism: Autism As a Source of Wisdom*. London: Jessica Kingsley Publishers.

McGregor, E., Nunez, M., Cebula, K., & Gomez, J.C. (2008). Seeking Coherence in Autism: from fMRI to Intervention. In E. McGregor, M. Nunez, K. Cebula, & J. C. Gomez (Eds.), *Autism: An Integrated View from Neurocognitive, Clinical, and Intervention Research* (pp. 1-19). Malden, MA: Blackwell Publishing.

Notbohm, E., & Zysk, V. (2004). *1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorder*. Arlington, TX: Future Horizons Inc.

Novella, S. (2008, April 16) "The Increase in Autism Diagnoses: Two Hypotheses." *Science-Based Medicine*.

Sarris, M. (2015, April 29) "Are Girls With Autism Hiding in Plain Sight?" *Interactive Autism Network*.

TED. (2014, November 21). *Rosie King: How Autism Freed Me to Be Myself* [Video file]. Retrieved from <https://www.youtube.com/watch?v=jQ95xlZeHo8>

TEDx Talks. (2015, May 4). *Benjamin Tarasewicz: Breaking barriers of autism: the power of kindness and friendship* [Video file]. Retrieved from <https://www.youtube.com/watch?v=r05BUkOfOk8>

TEDx Talks. (2013, June 16) *Chris Varney: Autism- How My Unstoppable Mother Proved the Experts Wrong* [Video file]. Retrieved from <https://www.youtube.com/watch?v=T1HQKB2txgY>