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Honors

Attitudes Towards Autism in Healthcare and in Society

The term autism is thrown around without much understanding about what it entirely means or even where it comes from. Hans Asperger, a psychologist, and Leo Kanner, a child psychiatrist, were the individuals who originally coined the term. Kanner describes the reasoning more:

“Human beings normally live in constant interaction with their environment, and react to it continually. However, ‘autists’ have severely disturbed and considerably limited interaction. The autist only himself (cf. the Greek word *autos*) and is not an active member of a greater organism which he is influenced by and which influences constantly” (Davis, “The Disability” 460).

Kanner also was the first person to suggest that parents were maybe to blame for the child’s autism. He thought that autistic kids came from parents that were “cold and rational” and who only came away from these characteristics long enough to actually make the child. This led to him also coining the phrase “refrigerator mother.” He did not always claim that he was behind these notions, but they still caused quite a stir. This was mostly because scientists wanted to believe that autism was an organic disorder, but without any sort of a “confirmed biological marker,” this was hard to convince others that this theory had any merit (Murray 54).

Another individual had a similar contribution to the way autism is viewed today and his name is Bruno Bettelheim. He was a Viennese Jew that lived through two different concentration camp experiences. Bettelheim was only released due to some

weird circumstances where Adolf Hitler decided to let some camp inmates go on his 50th birthday. His time within the camps was used to form his views on autism. He saw how dramatically the camp affected everyone and explained that the inmates overall looked quite isolated and withdrawn. This reminded him of autistic children. Therefore he came to believe the relationship between autistic kids and their mothers and fathers was a reflection of the relationship between the individuals imprisoned in the concentration camps and the people who ran the camps (Murray 55-56). This only emphasized Kanner's original opinion that families were responsible for the child's disorder causing stigma for parents of autistic children.

Overall the idea of autism remained relatively unknown to the everyday person for many years after Kanner's and Asperger's original identifications (made in the 1940s). Autism was briefly mentioned in the Diagnostic Statistic Manual (DSM) as part of the criteria for a separate disorder, childhood schizophrenia. It was not until the DSM's 3rd edition in 1980 that Autism had its own diagnosis and criteria (Davis, "The Disability" 461).

It has been said that psychiatric disorders typically tend to express an "excessive version" of one mannerism or another that could even be considered "socially desirable." A couple of examples of this includes anorexia, which is the extreme desire to be thin, and ADHD, which very plainly could be described as having extra amounts of energy and motion. When looking at autism in this light, one could describe it as the extreme expression of independence, which a lot of people would probably deem as a truly desirable characteristic. Although today's American society does highly respect an independent individual because they represent two important factors such as liberty and

freedom, autism also brings fear because it is then associated with loneliness and seclusion (Davis, "The Disability" 461).

This fear has led to not only a great misunderstanding of autism, but also something known as the war on autism. Fear is typically generated by the unknown and often people do not have enough knowledge on it to understand what it is or what it entails. Certain public or political statements have the power to increase this fear and it can lead to devastating circumstances. The Center for Disease Control and Prevention (CDC) stated that autism had reached a prevalence of 1 in 110 in 2014, and continued on to state that this was "an urgent public health concern" (McGuire 55). Even though plenty of social theorists have shown that the increase in prevalence rates has a lot to do with the contextual changes in how autism is presented in society, autism is often still described as an "epidemic." Unfortunately the term "epidemic" is truly influential and warrants a specific reaction. Epidemics are associated with terrifying, infectious illnesses such as the plague. The plague is something that takes away your loved ones and can negatively impact everyone it touches. Even though autism is nothing like the plague, this mindset conjures a wide sense of panic, which then leads to the association of autism with fatality (McGuire 56). The panic becomes so great that it causes some mothers to actually kill their child because they either are autistic or are showing "early signs" of autism (McGuire 5). To be fair, there is a lot that is unknown about autism. There are no known direct causes and no known cures. It is very debatable whether there should be any cures, but this is also because a lot of individuals do not understand what the typical behaviors are for someone who is autistic let alone what an autistic lifestyle looks like.

It is stressful to have your child diagnosed with a disability that a lot of the population deems as not just socially unacceptable, but also worse than death. Parents in these situations require support and proper resources that will tell them what having a child with autism actually means. Perhaps even just a different way of looking at the disorder would be beneficial. Disability studies scholars mainly discuss two ways of viewing all disabilities. The first is the medical model, which focuses purely on curing or “fixing” the disability and views the disability or person as the “problem.” The second is the social model which views disability as socially constructed and states that any impairments that are associated with the disability depend on the environment (Davis, “The Disability” 462). While there are a lot of other models out there in society that people tend to cling to, all of them stem from either the medical or social model.

In healthcare today, there is a widely used model that stems from the medical model known as the individual model. It should be noted that not all those who work within the field of healthcare adhere to this model. The individual model views disability as a “problem” and approaches it as a “personal tragedy” that only happens to some very unfortunate individuals. This leads to a person’s disability becoming their defining feature. It also leads health professionals to only look for cures (Durell 20). It can be argued that individualizing medicine does make sense. It can work well as a person-centered care approach, but with the amount of power health care professionals have, this mentality can truly influence how a patient views their own health concerns. Some disability scholars have made a point that incorporating aspects of the social model would help healthcare professionals become more informed when working with their disabled patients. The social model also has its own critiques, but it could allow health

professionals to not force their own view concerning disabilities on all their patients (Durell 21).

There was a study that actually created a method that was able to measure medical students' attitudes towards people with disabilities. It was administered to 342 medical students and there were five components to it. It was able to identify how comfortable students were working with disabled patients as well as negative and positive attitudes toward disabilities students and professionals might have. The study pointed out that the U.S. Census Bureau stated in 2005 that 18.7% of the population reported some sort of a disability. Also it was explained that having a negative attitude towards disability could lead to less than ideal outcomes for disabled patients in the level of care they receive. An example given was this: perhaps a doctor did not find it necessary to perform a pelvic exam on a female patient who was disabled because the doctor made the assumption that the patient could not actually be sexually active (Symons 251). This is a common assumption that is unfortunately quite ignorant. Disabled people are not asexual beings and beliefs like that are damaging socially, and it could be argued even more damaging for their physical health in this case. The result of the study showed that many primary care physicians conveyed a high level of discomfort when working with disabled patients. Plus, in general, clinicians had negative attitudes harbored towards disabilities. The study also revealed that this was mostly due to lack of exposure and training when it came to interacting to those with disabilities. Specifically, students in health care professional schooling programs felt especially uncomfortable and felt negatively about disabilities in general. But this seemed to change when they had the opportunity to have more experience with disabilities. Despite this evidence, this topic is hardly ever covered

in medical schools (Symons 254-255). This is similar to the issue addressed earlier concerning the unknowns of autism. There are so many people who are just unfamiliar with disabilities in general and therefore are uncomfortable because it is something they claim to really know nothing about.

Arguably the best way to find more out about autism is to read works by those who are autistic and actually listen to what they have to say for their own disorder. A great resource for this is Jim Sinclair. He is autistic and advocates for himself and others with autism. He provides us with an opportunity to try and see into the world of autism, and give us a better representation than any of us could have come up with on our own without his insight or others who are also autistic. In his work, “Don’t Mourn For Us,” Sinclair describes how traumatic it can be for parents to learn that their child is autistic. He explains that parents go through a grieving period over the “normal” child that they did not end up having. While some amount of grief is typical and understandable, Sinclair argues that it has to be kept distinct from how they actually identify the autistic child that they do have. This is because this child still needs support and if the parents are not able to stop looking at their child’s autism as a foundation for their woe, it can damage the relationship between the child and the parents. Sinclair also describes what autism actually is to someone who is autistic (Sinclair, par.1-3). He says:

“Autism isn't something a person *has*, or a ‘shell’ that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the

person--and if it were possible, the person you'd have left would not be the same person you started with” (Sinclair, Autism is not an appendage).

This is a very powerful statement. It can entirely change someone’s point of view on this disorder. Sinclair goes on to state that it is vital for people to understand autism as “a way of being” because it cannot actually be detached from the person. He explains that once someone is able to comprehend this notion, they would understand when parents say that they wish their child was not autistic, that they are actually expressing that they want a completely different child and that their existing child would not actually exist. This is Sinclair’s way of letting his audience know what he and other people with autism hear when statements like this are made (Sinclair, Autism is not an appendage). This means that how society views autism as a whole can be very hurtful to those who actually have the disorder. Discussions of cures have the same implications and perhaps it is time that society starts learning to accept autistic people for who they are rather than who they “should” be.

A lot of people struggle to communicate with autistic people. Family members often have trouble relating to their autistic child as well. This could arguably contribute quite a bit to the grieving period that parents go through when their child is diagnosed. Sinclair explains that the reason parents find it so challenging to relate to their child is because they are trying to communicate through their own understanding. He explains that this is the problem because there is this assumption that a “shared system” is being used. However, those with autism do not actually grasp the language that most of society uses, therefore the message the parents are trying to relay will not necessarily come across the same way, if it goes through at all. To people with autism, the language shared

by most individuals is native to them. Sinclair explains this and says that to actually get through to them, people will have to go back to a much more basic level of communication so the information can translate more clearly (Sinclair, Autism is not an impenetrable wall). This is an important factor to consider when interacting with autistic people. Communication is key and without this shared ability, it is much more challenging to “fit in” within society. Also, without people who are patient and willing enough to appropriately communicate with autistic people, the amount of information unknown will remain the same and conditions will stay as they are as well.

Sinclair also says:

“This is what I think autism societies should be about: not mourning for what never was, but exploration of what is. We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support. Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us” (Sinclair, Autism is not death).

It is up to society to reshape its views on autism and make room for people like Jim Sinclair. Autistic people should not be shut out or be forced to change who they are just because they do not fit into society's socially constructed “normal” box. Sinclair explains to his audience what the actual tragedy is. He says, “The tragedy is not that we're here, but that your world has no place for us to be” (Sinclair, Autism is not death). This can be eye opening for many people, and it should be. This is not something that is necessarily expected for all people to just inherently figure out on their own. But by taking the time expose oneself to topics such as the ones Sinclair discusses, anyone can become more informed and then the real change can begin.

It is also important for people to listen to family members of those with autism. They hopefully know their child best and will be their best advocates until they can self-advocate. A good resource for this point of view is Rachel Robertson. She is a single parent of an autistic child and she wrote a book about her and her son's experiences titled, "Reaching One Thousand." There are several topics in the book that accurately represent what Sinclair discusses in his works. Robertson went through the normal grieving period when her son was initially diagnosed, but was able to move past it. Later on in her book, she argues that it is "impossibly hard" for someone without autism to see and decode the world in the same way that an autistic person would. Robertson also argues that hearing someone with autism describe it is not necessarily enough. Her son was very interested in numbers and she suggested that this was his way of "surviving" in the world; the numbers created structure for him (Robertson 24).

At one point, her son went through sensory integration therapy and she honestly believed some of it did make a difference. Robertson had concerns that some of the therapies might be "reprogramming" her son's brain. She finally decided to verbally express her worries to the professional that was working with them through this process. While the professional was polite, Robertson came out of the conversation feeling as though the professional believed her to be foolish and a bit irrational. She just wanted what was best for her son and did not want any of the therapies to take away part of who he was (Robertson 42). The fears that Robertson was experiencing were healthy and the professional was not as supportive or as understanding as one might have hoped for. She should not have had to leave that conversation feeling judged. Being a mom that cares and knows her son that well is a good thing and she should have been able to discuss her

thought processes with a professional who is supposed to be have more knowledge on these subjects.

Robertson makes a very striking comparison between autism and cancer in her book. She states that, “autism is to disability what cancer is to illness” (Robertson 50). She explains that there are several reasons behind this statement, one of which is that autism has the same ‘oh no’ status that cancer does. It has the ability to strike fear into people in similar ways. Also, people are told to fight autism just as they are told to fight cancer. Robertson then poses a question, if parents of those with Down syndrome or cerebral palsy would be told the same thing (to fight their child’s disorder), or if they would instead be told to work hard on fulfilling their child’s potential with the life they have been given (Robertson 51). This comparison relates to the issue mentioned earlier when the CDC referred to autism as an “epidemic.” Too often society views autism as one of the worst things a child could ever be diagnosed with. This has a lot to do with the grieving period that Sinclair discusses, but it can be argued that it is the duty of professionals, in and out of healthcare, to help parents transition out of this stage. Even using terms such as disabled or autistic is avoided by parents due to how limiting and stigmatizing they can be. Robertson hopes stigma can one day be removed from the term autism. She states, “As people with disabilities have pointed out, if the world were structured differently, then the needs of someone with a disability would not be ‘special’ at all” (Robertson 52). Her statement mirrors the social model approach. This mentality shows that after all the research she has done herself; Robertson has developed a healthy and productive view of her son’s disability. Because of this, she does not accept the

viewpoint that anything about her son is an error. Instead, she believes her son is his “true self” and is exactly who he is supposed to be.

During a doctor’s appointment concerning her son, Robertson expressed her beliefs to the pediatrician. His response was this, “There’s no such thing as a true self, though, is there? We mold our children and we want to encourage yours to be less autistic, more normal. Isn’t that what you want” (Robertson 66)? This is a very nonproductive way of viewing her son’s disability and was not an empathetic response either. Not only that, but questioning Robertson’s view as not being best for her child when she is actually just trying to accept who he is as person, is inappropriate. This physician is forcing his/her own views about autism on Robertson and her son and has not separated himself/herself enough to be encouraging in a way that would be helpful. This doctor seemed to have tunnel vision and was only seeing the autism through a medical model lens. It would be beneficial for his/her opinion to be informed with at least some aspects of the social model because in that conversation, the two adults were on two opposite sides of the spectrum. Without any sort of middle ground, interactions like that are not beneficial for Robertson or her son.

There are different approaches and models that can help form this middle ground. An example of an underlying concept is referred to as bioculture, which is a combination of human biology with socio-cultural context. To use a biocultural lens is to look at science with all historical and cultural context. Using both perspectives leads to the ability to gain the mutual benefits of each. Those who propose this approach say, “The biological without the cultural, or the cultural without the biological, is doomed to be reductionist at best and inaccurate at worst” (Davis, “Biocultures” 411). The idea of

bioculture is to try to utilize the humanities with the sciences to have a more complete understanding and approach to topics such as autism. Bioculture challenges the idea that some facts are considered “hard” while others are considered “soft.” It does not want to ignore what data supports through proper experiments, but it does want humanities to not just be classified as “the study of values and feelings” (Davis, “Biocultures” 413). This approach is supposed to be more productive and have more validity to it as well.

Biocultures warrant a society of interpreters, from different masteries, that are willing to communicate and learn from one another. It is mostly a model that revolves around dialogue because it believes that the two approaches are “incomplete” when they stand alone (Davis, “Biocultures” 414-417). This can easily be translated to the controversy between the medical and social model. The medical model is the more scientific approach and the social model has more of a humanities element to it. Being too set in one mindset would be relatively narrow-minded and perhaps even ignorant. Each model has its strengths and weaknesses and both have the power to inform people on approaches to better understanding disability. The medical model would not be able to stand on its own in a productive manner without elements from the social model and vice versa.

Incorporating both would be beneficial both socially and medically. Fortunately there is a model out there that helps bridge the gap between the two opposing viewpoints. It is known as the affirmation model and it takes a non-tragic approach to both disability and impairment. It also scraps the notion that having a disability is automatically negative (McCormack, “The Affirmation” 157-158).

To take a look at how the affirmation model would actually inform a health care profession in a productive way, one could look into occupational therapy for a great

example. The field of occupational therapy (OT) revolves around client-centered practice. Their code ethics includes 7 principles that are as follows: beneficence, nonmaleficence, autonomy and confidentiality, social justice, procedural justice, veracity, and fidelity. These principles help guide the client-centered practice each OT is expected to perform (O'Brien 70-72). This is the profession I am going into and as much as I love OT, I do know that most people do not really know what it is. I had to come up with a definition for an introduction course I took and it not only outlines what OT is, but provides examples as well. I defined OT as a field that helps individuals perform activities or occupations that are meaningful to them and who, for one reason or another, are not capable of doing so themselves, with the end goal being that the individuals are able to lead a more fulfilling, healthy, and happy life. For example, say a child with autism wants to play with other children his/her own age. Playing is the occupation that is significant to this child and an occupational therapist can work with this child and help this want become a reality. Occupations can vary from wants to needs that fill one's day and bring value to one's life. Examples include but are not limited to: dressing independently, eating independently, making friends, playing sports, etc. OTs believe that helping individuals achieve their goals of being able to perform occupations specifically important to them improves their health and quality of life.

One criticism of the client-centered mentality is that without OTs having more of a disability studies perspective of disability, their viewpoints on disabled individuals will not be complete. One simple example is that of person-first language. Health professionals are currently taught that this is the most appropriate way to address disabilities. Conversely, some disability studies scholars view person-first language such

as “people with disabilities” as “an offensive term, promoted by powerful nondisabled people to emphasize that disability is part of the person rather than a social construct” (McCormack, “Can” 339). It is also argued that using person-first language suggests that the individual is “one with the disability” and rather a “disabled person” is an individual who is disabled by outside effects such as the environment (McCormack, “Can” 339). The latter would be a representation of a social model approach while the person-first language is argued to be more of a medical model approach. Sinclair also does not find person-first language to be the most appropriate. He views person-first language as a way of disconnecting the person from the disability. Sinclair goes on to say, “It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person” (McGuire 188). This emphasizes the automatic negative connotation that is too often associated with disabilities.

There are some disability scholars that believe the field of OT to be “oppressive” due to its inclination to use the medical model within its practice approach. It is not just OT that faces this criticism; it is all rehabilitation professions due to their “person-fixing rather than context-changing” mentality (McCormack, “Can” 340). The basis of this assessment is because while in the mindset of the medical model, too often the disability is usually only thought of in a physiological or psychological sense rather than a unique situation that varies from individual to individual. This leads to the argument that the OT profession as a whole has not responded as quickly as necessary to the social model approach to disabilities, and this can be seen even in the textbooks used by OT students. But it has been suggested that if an OT does take the approach of actually individualizing disability, it could still lead to focusing too much on fixing the individual deficits instead

of taking a wider approach that looks at what society is able to provide. This is not to say that disability theory cannot contribute to the practice of OTs. Disability theorists actually believe that the academic knowledge of disability studies can help OTs take a look at their own assumptions concerning disability and help form a better professional involvement with disabled individuals. By doing this, OTs will be able to make sure that their practice is more perceptive towards the point of view of their clients and their “actual lived experiences of disability” (McCormack, “Can” 340).

Disability scholars go on to suggest that perhaps a better model for OTs to incorporate into their client-centered practice is the affirmation model. It nicely complements the field of OT because it emphasizes how vital occupations and everyday life activities are to someone’s identity (McCormack, “The Affirmation” 155-157). This supports the bioculture concept too because the field of OT and the patients involved would benefit most from using both a medical and social model approach. Thus the affirmation model is an excellent tool for OTs and most likely other healthcare professionals too. I plan to take what I have learned both from my major, physiology, and my minor, disability studies, to further inform my future practice of OT in a biocultural way that will hopefully prove to be most beneficial for my clients and patients.

In conclusion, autism is not something that can just be overlooked and society, as a whole, has a job to do. People should come to the realization that autism and the experience of autism is not something that only happens “out there” (Davidson 6). It will touch the lives of most of the population, but especially so within the healthcare field. Autism is a very personalized disorder and therefore will present differently in each autistic person (Davidson 12). If people are not willing to expose themselves to autism or

even educate themselves on the matter, it is then up to them to at least approach autism with a more open mindset. Autistic individuals are waiting for society to welcome them with open arms and there is no excuse that this cannot happen. The mindsets of parents have to evolve past the initial grieving period for a healthy relationship to form. For this to effectively happen, parents need support from professionals. Therefore, health care professionals should learn to develop, at the very least, a neutral point of view on autism. A good way to accomplish this is with the affirmation model, which may take more of a social model approach but it still incorporates important aspects of the medical model. This will hopefully develop a supportive environment where open dialogue can take place without judgment. This would be most productive for those with autism as well as disabled people as a whole.

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