Raising Children on the Autism Spectrum: The Impact of Socioeconomic Differences on Treatment and “Recovery”

Lisa Sendrow
Advisor: Braulio Muñoz

May 2\textsuperscript{nd}, 2013
# Table of Contents

Abstract 3
Acknowledgments 4
Introduction 5
Chapter 1 41
Chapter 2 52
Chapter 3 67
Chapter 4 93
Conclusion 117
Appendix A 136
Appendix B 138
Appendix C 139
Appendix D 141
Abstract

Raising Children on the Autism Spectrum: The Impact of Socioeconomic Differences on Treatment and “Recovery”
Lisa Sendrow
Advisor: Braulio Muñoz

For this paper, I focus on the disparities that exist from raising children with autism from marginalized communities. Anthropology has an important role to play in the ways that members of society view people with autism, and to navigate this concept, I interviewed fourteen therapists, parents, program directors, researchers and social workers who have invested time and energy in working with children on the spectrum. I also used books and articles to supplement interviews. Of particular importance was how income, culture, and race affected the treatment and care that the children would receive, and how parents would try to overcome societal obstacles to obtain the best care. I found that demographics and socioeconomic background highly impacted treatment.
Acknowledgements

First, I would like to thank Professor Braulio Muñoz for being a patient and helpful advisor, as well as Professor Maya Nadkarni for also listening to me panic and teaching me how to kill my darlings. They both have given a lot of time and energy into my own stresses. Professor Mike Reay was also amazing in helping me get through the IRB process, and I truly appreciate him—without approval, I would not have been able to do this research. Also, the other professors in the Sociology/Anthropology department as well as Rose Maio have been extremely helpful in the thesis process.

I thank my mom for pushing me hard to succeed, my aunt and cousin who inspired me to proceed with this topic, and for the rest of my family for their unconditional love and support. Amo a todos ustedes.

I thank my friends for putting up with my craziness and mood swings, especially Emily Richardson, Ben Kapilow, Layla Helwa, Joanna Venator, and Marcus Mello. Those meals and thesis therapy definitely kept me healthy throughout the process.

I would also most of all like to thank all of the people who allowed me to interview them and welcome me into personal parts of their lives so that we can benefit families and children who are struggling with autism care.

Thank you everyone for reaffirming my social justice values.
Introduction

“People don’t seem to understand that [you can still love people with autism] and they always talk about ‘those’ people and that really gets to me. ‘Those’ people, as if they’re not really human beings. They’re this other breed of people. There’s human beings and there’s animals and there’s insects and there’s ‘those’ people. They’re just a separate identity again.”

~ Francesca Bierens, A Spectrum of Light, 32

One mother, G, recounted to me that getting the diagnosis for her daughter was similar to the feeling that, “something was throwing a brick in my stomach. It was absolutely devastating” (G, 1/12/13). She held her coffee and tears began to roll down her face while we were sitting in a Starbucks just outside of town. G is an immigrant from the United Kingdom with three children, and her youngest was diagnosed with autism at five years old. Her daughter is now living in an institution that G pays for out-of-pocket, and the institution is close enough to home that G can still visit. Her daughter who once used to be “very social...just inappropriately social,” is now, “drugged and she is gaining so much weight and she’s lost life in her eyes and she used to have so much energy, but she was always so smiley and a little sunshine girl. Now she shuffles a lot, she has no life, and she’s huge and that’s because of the medication. That’s how they cope with her...And we’re in no position – if I say no, I don’t know how they would treat my daughter. I had to take their word for everything...I reintroduced medication and I felt I had to do it, I didn’t want to do it, I had to” (G, 1/12/13).

Every parent wants a typical, healthy child, who will develop at the rate of their peers, and furthermore, a child who can be happy and lead a great life. So when they hear the words “your child has autism,” many are scared or devastated. What does it mean to have an autistic child? What did they do wrong, if anything? How did it happen? They are desperate to find causes, answers, and lastly, solutions. They try multiple treatments, or do not know where to begin with treatment. The best treatments can also be expensive, and parents try to find other
ways to treat their child and seek a miracle cure to help their child get better. But there is no miracle cure for autism.

Low-income families especially struggle. Many issues plague lower-income families that are not prevalent in the lives of all families. I argue that low-income parents struggle raising children with autism because they lack the general resources that are available through the ability to purchase such care. These resources include having schools that have enough staff for support or funds for students with disabilities, therapists who take their health insurance or accept their lack of insurance, transportation, and other barriers. Through these restrictions, we must acknowledge their inability to get the best care, and find ways to make it easier.

Society is afraid to talk about disability, especially when it comes to disabilities of underserved populations. I am not surprised as to how hard it was to find research for my thesis with this knowledge. I had to make up for the lack of research through my own interviews and research outside of the realm of books and articles. I went to several talks, interviewed people from all sides of the spectrum, except for children. And the people who are underserved in our society have more issues when it comes to communication about disability that affects their family. In a way, anthropologists have a large role to serve with underserved populations. “For anthropology to address disability adequately, the field would have to attend to the “daily life and personal experience” of disabled people more systematically and deliberately than it has in the past, and would have to do so in the context of the “cultural values” and other factors that shape experience.” (Linton, 1998: 103) This is the challenge, and what I will accomplish in my thesis. I explore the lives of children with autism and their caregivers.

Autism research expands all the time, and is an extremely controversial subject. It is generally researched from a more scientific and clinical perspective when we try to figure out if
it is genetics or vaccines that cause autism. Hint: it’s not vaccines. This theory has been disproven and debunked by various doctors, and therapists have told me that they are worried about children with autism not getting vaccines because they are not protected against other diseases.

Briefly, autism is a very individualized disability, and not all children with autism need the same treatment or have the same qualities. However, some characteristics that define autism are, “problems with speech and language, difficulties relating to others, and repetitive activities” (Ariel, 2006:15). This includes a lack of eye-contact and lack of speech as common characteristics, but of course, autism looks different in each child. Other theorists say that people with autism lack a theory of mind.

There is social death and suffering of people with disabilities, and they are kept from our society as being social actors. They are not treated properly by society, whether they are walking around in public where they are constantly judged or in the hospital receiving care. Yet, “not all psychiatric disorder is social suffering, nor does social suffering always create or intensify psychiatric disorder. The framework of suffering also makes less useful the concept of medicalization, which has become so powerful in our time” (Inhorn and Wentzell, 2012: 119). In fact, children with autism do not always recognize enough social cues to recognize their social death or suffering. But for those around the children, there is a strong sense of injustice carried out by the medical system and our social structure.

This is why I chose to pursue a medical anthropology project about autism so that I could research how income and cultural background affect diagnosis and how families are treated based on those background descriptors. Medical anthropology is important in relationship to suffering. “Medical anthropologists study human suffering, as well as the medical systems in
place to alleviate that suffering...Their work points to the differences in the ways that bodies count: who falls ill and why; who has access to health resources; and where healing is sought. They have examined questions of stigma, marginality, and the disabled body” (Inhorn and Wentzell, 2012: 2). Medical anthropologists are also particularly interested in the way that background can affect treatment, just as I am researching how socioeconomic background affects the treatment of autism. However, medical anthropologists have widely ignored the struggles of low-income families, even though there is much literature on psychiatric treatment (Inhorn and Wentzell, 2012: 123), which is why my research is particularly important in the field. There is not enough research on inadequate services and of experiences of children with autism, and people of all disabilities, coming from low-income societies.

Anthropology works to humanize subjects with autism, show that empathy is practice-based by observing and communicating the struggles of people of various backgrounds, and show how autism is affected by institutional settings. “Anthropology could shed light on what happens when this [observation of people of oppressed backgrounds] ethical imperative is not met, when someone is incapable or unwilling to adopt the dominant medical knowledge and participate in ratified practices of biomedical consumption” (Solomon, 2010: 246). Plus, “remarkably little attention has focused on the financial issues faced by families that have a child with autism” (Sharpe, 2007: 248). Anthropology has a duty to criticize the practices of our society in actively oppressing people, and when it comes to autism, anthropology can shed light on financial problems that are faced by families. Therefore, for my thesis, I am going to utilize this research to humanize our underserved populations and also our disabled community that does not have the best access to care. My thesis is about how children of families in marginalized communities are not given the best treatment for their autism, and are limited because of their
race, class, and relationship to their marginalized identity. Oftentimes, the communities are not extremely supportive either, Medicaid and health insurance does not cover treatment, and schools do not always follow protocol. Socioeconomic background impacts the care your child will receive, and leads to disparities in diagnosis, treatment and support across various axes of inequality.

This is very different from the way that autism can be portrayed in films and books. As one parent notes, "I found the cheerful tone of several books as well as the upbeat Hollywood endings to be utterly divorced from the realities I was confronting" (Ariel, 2006: 30). The reality is that autism is not cheerful for parents who struggle to get the best care for their children. An anthropologist who interviewed parents on their perspectives wrote that, "'Rain Man' has done a few good things but it has also done a number of bad things. I said to somebody the other day that my daughter's autistic and immediately he said, 'Oh, so she can count, can she?' and 'What can she do? What special abilities has she got?' There's not enough education out there. That just comes down to the basic old fact of money and the ability for people in power to see the need for some sort of National Centre to provide education" (Beirens, 2009: 37). Parents have to constantly handle questions like, "is your child like Rainman?" or, "why does your child seem so social?" The stigmas attached to autism bear significance in the way we see autism and treat children with autism. The parents begin to question themselves as well, and question the challenges that their children currently face and will face as they grow up. And they realize that at a young age, there are more challenges that need to be faced to help them in the future. This is hard as there are many differences in autistic children and personalities within the children themselves as they grow up or have problems in school or have to deal with other events and sequences of events that may affect their struggles.
Part of the reason why I chose this topic is very personal. When I was 12, my cousin who was two years younger than me was diagnosed with various disorders: schizophrenia, bipolar disorder, ADHD, dyslexia; no one was sure what he had. He was also a recent immigrant from Mexico, without health insurance and with my aunt worrying more about putting food on the table and helping him lead a comfortable life that she could hardly afford. He and my aunt were extremely manipulated by the systems that are in place, where he was constantly given medications that were overpriced, and he lacked insurance to cover these costs. So my aunt, who worked three jobs at a time, had to fight for my cousin to get this medication. The school district did not willingly pay for his special education and specialized schools, my mom had to be there to battle with the school, and I often had to go to meetings when my mom did not have the time to translate and to also fight for my aunt. They “concluded” his diagnosis later, meaning that there is still argument about what he has eight years later, at the expense of my aunt and my wonderful mother, who put so much time, money, and energy into his health. I became very interested in working with children with disabilities, meeting some people in his school and in the hospitals. I tutored children with various disabilities as well because they had more difficulties in school and not as many people were as sensitive towards their disabilities. One of my tutees was named Duncan, and he was a high-functioning autist. He always sat alone, and the other boys would bully him constantly and he didn’t know how to react. He was confused, and it was hard for me to believe that he couldn’t find a true sense of happiness being around kids his age.

Organizations are coming in to try to speak for children and people with autism. For example, Autism Speaks is an advocate for people with autism, but no one in the organization actually has autism. This is a problem with disability rights in general, where many advocates are
not actually afflicted with the disability. This is a fundamental problem where, disabled people’s voices are almost completely absent from this picture, and so the understanding of disabled people’s place in these situations is filtered through the experience of people who have never been in that place” (Linton, 1998: 37). Again, this is where anthropologists can relate the issues of disability and autism in particular for the general public to understand and discuss how disability culture is prevalent in our lives. It is the job of anthropologists to try to stop oppression of people with disabilities instead of trying to control and manipulate people with disabilities. For too long, people with disabilities have been excluded from social and cultural events, and with this thesis, I want people to take away that people with disabilities, and in particular autism, should not be excluded from the opportunities in our society.

This topic has definitely been hard to undertake, but I want this research to become something bigger for me to tackle as I have realized why autism, and other mental disorders, are so important to work with. I have transformed my idea in many ways after reading various books and articles, and talking to many people about the topic. This topic has been almost as hard to write about as it is to understand, and I have condensed it in a way to make it easier for readers to understand the importance of the topic for all people with disabilities and all people who are seeking better health care.

Questions

Before getting into issues of class and the intersections of race, I think it is important to delve into the issue of what it means to be autistic for families who are coming from low-income backgrounds and in general.
Now that autism has become even more confusing about what it means to be autistic, the next question I will look at is the idea of: who constructs normality? Is it possible to have autistic traits and not have autism? Who decides what it means to act normally? And then how do we discuss autism in that respect?

This leads to another question about whether or not autism can be considered “made up”? Or, are some children misdiagnosed, or not diagnosed at all? There are apparently a growing number of parents who are trying to get their children diagnosed as autistic to explain problems that their children may have, but this is not extremely common. The diagnoses of autism have increased significantly to a point where now 1 in 88 children are diagnosed, but the range is different and autism, again, looks different in different people. So the way the medical world has defined autism has changed drastically and has included different traits that the children can express. Initially, autism was not diagnosed as frequently, and much of this is because children with autism did not look different. They have the same physical traits as neurotypical children, but do not share social traits. In fact, one medical director, B, says that, “I see [autism] as primarily a disorder of social development…autism itself is related to a primary lack of understanding of social things that come naturally to 90% plus of the population. Our brains are wired so that we naturally social geniuses – we just happen to be wired for social things and people with autism are not. That is really the primary problem that they have” (B, 2/15/13). This is what really differentiates neurotypical children and children with autism, and this invisibility diminishes their struggles. Health insurance also does not always cover the treatment of children with autism and the care that they need. They need special programs in schools and require more attention than non-autistic children.
This is a sensitive issue because this is directly related to the ways in which anthropologists discuss certain topics with parents. Children with autism are drastically different from non-autistic children in the way they relate to other people and interact as well as act in general. Many parents of children with autism are very aware of the lack of sensitivity towards their children and realize that many other parents do not know how to give advice because they lack understanding. It is one of those issues that you need to be a part of to understand how it works and take children to treatment and put them in special programs. Many parents of non-autistic children like to give advice such as “oh my child also used to throw tantrums, your child will grow out of that stage soon,” when in reality, the child will not stop throwing tantrums soon. And because of this, there is a stigma attached to the parents of children with autism. When they are in public and the children throw tantrums or are hitting themselves, they are seen as bad parents and are embarrassed. Many parents learn to ignore the people around them who either stare or pretend that nothing is happening. Most parents would like it if other people were sensitive, and parents do want people around them to know certain ways to treat them.

The next question regards how the child should be trained in the classroom. Many parents struggle with the first part of whether the child should be placed in a special education classroom, especially when the child is working at a higher level, or if they should be in the more normalized classrooms where it is more likely that the child will be bullied. There are also some schools that are specialized for autistic children, but some parents would rather have children be in the regular school district so that they can learn socializing skills. Some schools provide aid to the children, but other schools are not as specialized. And sometimes the specialized schools, whether or not they are specifically for autistic children, do not have trained teachers or teachers that are trained to do unwanted things. One school, called the Judge Rotenberg Center, uses
electric shock on the students as a training mechanism. There are many different ways for children with autism to be educated.

What is the right way to treat a child with autism? And how can it be made more affordable to families? Is there one specific way to treat children? Is there a best way? Are there enough trained specialists who are also affordable? Are there centers parents can use to help their children? Are some better than others? We have to wonder if there is better treatment to be given and consider that parents are probably desperate to find the best treatment for their child. And while I said before that there is no magic bullet, I will discuss in my thesis the different types of treatments, what works, what doesn’t work, and the myths that arise out of this desperation.

How do we construct citizenship? Does citizenship look different for people with disabilities/autistic children? Different theorists have talked about this issue, in particular Michel Foucault, Erving Goffman, Michael Bérubé, and Martha Nussbaum who uses the work of other theorists to create her own theories. While I will discuss these theories in my literature review, it is clear from these works that citizenship is not the same for children with autism. Children with autism are not treated with equal rights in our society. Whether or not they come from a lower-income family, they do not always get the best care possible, and their humanity is diminished.

In this same sense, and in a bit of a more in depth way, we see how autistic children are losing their rights, especially in terms of the classroom setting and also in treatment by society. They are seen as different people, even as a different species in many cases. There is a lot of bullying, especially if the children are in typical classrooms. Autistic children do not look different, so children cannot tell that autistic children have any sort of disability. They are just seen as strange, and because of that, many kids bully children with autism who may not always understand the bullying.
This leads to the ultimate idea of how class and race affect raising children with autism. How does race play a factor? Can children from lower-income families get the best treatment? What about health insurance? How can we work with parents who are trying to help their children but do not know where to put their resources? I will show that race and income play a factor in the treatment that children can get, and how parents are not given the resources to try to help their children.

Chapter Construction

For the first chapter, I am writing about perceptions of autism, social action, and the worries of parents in the socialization of their children. Parents are typically blamed for not raising their children well, and question their parenting style. However, parents always worry about their kids, whether it is about bullying or abuse, or how they socialized. Children with autism cannot communicate in the same way as typical children. Throughout my thesis, I say “typical” instead of “normal” because “normal” is a term constructed by our society that removes children from their agency. Anthropologists must consider what we can do to help parents and children, how we can educate people about disabilities, and also the treatment that children will get in all types of schools, whether public or private. I argue in this chapter that children with autism and their parents need a more specialized sort of treatment, and especially from lower-income backgrounds, parents are much more pressured to find good care for their children.

The second chapter will be about punishment, citizenship, and ethical issues related to autism. Children with autism do not always get due justice and are not always treated with fairness. We must also begin to question our definition of justice and how it applies to children with autism. This relates to court cases that take place all the time for autistic children where
they do not get equal treatment, and where their honesty and reliability are questioned. Then, there are ethical issues in autism, along with guilt and shame for believing that we are not helping the children in the way that they need to be helped. Parents, therapists, and teachers do not believe that they have or can do enough, especially if they are not coming from an area or background where they can obtain resources. They are desperate to find some sort of resource for their children, and lose confidence in themselves. From low-income and Latino and Black backgrounds, there is more of a question of citizenship because these groups are already disadvantaged in our society. When disability is involved, there is a clearer sense of injustice and punishment that is prevalent in these groups.

The third chapter will be focused on the varied effects caused by coming from a low-income family. I chose this as my topic for various reasons. For low-income families, helping their child with autism is not always the most important factor. Some parents work multiple jobs, and they cannot put in the time or energy to help their child use the bathroom. Some parents cannot afford resources; others do not understand the resources. They may not even understand what autism is. Resources are also more generally directed towards families with a higher income. However, some places are starting to give grants to families who show need. Children from low-income families have to learn different skills, and lower-class families cannot provide the same skills because they do not have the time or money to train their kids. And for these reasons, they also typically get a later diagnosis and therefore less time to work with their children. The resources that families get also show a distinct difference in the office and school settings.

The fourth chapter will be about multiculturalism and race differences, with a focus on immigrants as well. Professionals say different things about racial minorities being either over or
underdiagnosed, but it seems that underdiagnosis is more prevalent. There are definitely differences in Black and Latino families, but it is not because autism is more prevalent in different races. Race is the factor that leads to misdiagnosis or no diagnosis at all. Stereotypes, but also location, are big factors in this determination. Because of racial differences, some families may also be stigmatized by doctors, and also the children will be diagnosed later. With cultural issues, there is also a wide difference coming from a different culture or religion that affects the ways in which the child can be helped. Religion especially plays a large role by the way in which God can see the child as a punishment or a blessing. In most cases, Latina mothers who have a child with autism believe that this makes them a better mother, or the mother is already a good person and God knows that. He wants the child to be in a good home. However, the punishment part of it comes from God wanting the mother to suffer because it is harder to raise children with autism. Then, most immigrants end up being part of the low-income community. They face a language barrier, do not know what is available to them, and need to find professionals who speak their language. They cannot understand what is available to them, or do not even know how to understand what autism is.

There is not much research done in blogs, articles, books, and autobiographies about raising children on the autism spectrum from an immigrant family, which is prevalent as more immigrants come to help their children and have a better life. They cannot always read or write, and do not have the resources to work. When they do know how to read or write, it is hard for them to find the time. And much like low-income families, there are other things that occupy their time and are more important to immigrant families that are not necessarily focused on their children. They do not have citizenship, and cannot get healthcare and cannot always pay the taxes, so they miss out on other programs that may be available to low-income families. They are
financially unable to get services. Most of the children were not taken to regular doctor checkups for the first three years of their life because of this lack of insurance. They also do not necessarily know other families or know about support groups for parents.

**Literature Review**

Unfortunately, for my research, there is not much prior research about being autistic from a lower socio-economic background. However, many authors tackle different issues related to autism, with statistical data about children with autism from different backgrounds, the connection of autism with anthropology, and views of parents.

One author, Francesca Bierens, wrote a book about the thoughts of parents of children with autism, taking a similar position as I'm taking by showing their struggles through various factors. However, her focus was on White, upper middle-class families and it was just based on thoughts of families. Her work is still extremely important though, and it is a clear demarcation of the struggles of parents in raising their children. She focuses on the various emotional parts of raising children with autism, talking about how families “have to work at not becoming isolated” (Bierens, 2009: 25) because autism can otherwise be very isolating, and how parents “commit [their lives] to this child and all [other parents] can do is turn around and say, ‘You should be doing this’…” (Bierens, 2009: 28). This deeply hurts the parents who work extremely hard to raise their child and love them, and other people do not understand the pain and heartache that they go through. Children with autism are dehumanized and become another breed of people with this isolationist perspective and by being treated more like animals.

Anthropology can further guide the study of autism in children and humanize the children. Anthropology is, “guided by the assumption that there exist forms of life radically
different from ours that are nonetheless fully human…” (Solomon, 2010: 244). Children with autism live a different life, but that does not diminish them of a human identity. Olga Solomon adds that, “the everyday practices of those affected by autism and their families and the production and recirculation of knowledge about autism in family, community, and institutional settings” (Solomon, 2010: 244). The way that the autistic identity is practiced is in a very institutional perspective, and also based on relationships. People learn about autism and treatment through other people, and this is the way that they communicate. However, from other more marginalized communities, there is not as much communication and also not as much diagnosis. Solomon says that,

“some social groups appear to be more and some less equal when it comes to receiving a diagnosis of ASD; thus being at risk for autism is not only a genetic issue because of family history but also deeply embedded in structures of health care access and delivery as well as in practices of caregiver-physician interaction in clinical encounters. There are children who are at risk not for being diagnosed with autism but rather for being misdiagnosed with other psychiatric conditions or not diagnosed at all. Population-level demographic studies, for example, indicate an unprecedented scale of health and service disparities in autism diagnosis for African American children. A national study that correlates the age of diagnosis in Medicaid-enrolled children with ASDs found that socio-demographic characteristics as well as local health care resources and state policies contribute to disparities in the age of diagnosis, a situation that requires rethinking what being “at risk for autism” means” (Solomon, 2010: 249).

This quote is essentially the basis of my entire thesis, and incredibly important to future anthropological research related to autism in marginalized communities. In it, the issues of Medicaid and health care access, and the disparities based on socioeconomic status are made prevalent and expresses that these differences create extreme inequalities for children who need treatment for autism. The stereotypes within these communities can also lead to the inaccuracies of diagnosis because there is a “strong influence of structural, sociocultural, and communicative processes that underlie seeing autism and generate disparities in autism diagnosis. Anthropology can make an important contribution to illuminating these processes” (Solomon, 2010: 249).
Anthropology has the ability to show the discrepancies of diagnosing autism and showing that stereotypes of communities devalues their struggles in receiving proper care.

In anthropology’s roots, anthropology has been ethnocentric and a way to save populations outside of the United States. One anthropologist, Richard Lieban, suggests that most medical anthropological work has been outside of the West (Sargent and Johnson, 1996: 356). I strive to include people of various cultural backgrounds in the United States in my thesis. Ethnocentrism has affected the way in which anthropologists investigate social issues, so “it is not surprising that ethnocentrism and allied ideas such as cultural relativism should be a routine part of the clinically applied anthropologist’s repertoire. Their centrality within anthropology is related to the need to understand peoples’ diverse beliefs and behaviors without imposing judgments from one’s own culture” (Sargent and Johnson, 1996: 105). Anthropologists cannot make assumptions about the diverse cultural backgrounds of people in a community. They cannot rely on their own understanding of culture to understand the culture of others. There are different sets of beliefs and practices within the different cultural backgrounds.

In many ways, children with autism are not seen as emotionally or economically priceless, and therefore, their value in society decreases due to societal expectations of their worth. Care for autism can be severely limited for some parents and children because of the ways in which society views autism. Because autism is essentially an invisible disorder to the public eye, there is not as much help for people with autism, and they are severely limited. For people of lower economic classes and of non-white races, help is severely limited and also not as well researched.

Books and articles about autism are outdated because research always adds new perspectives and theories. Primary articles and blogs and books are also generally not coming
from people of non-white races, lower classes, or immigrants, the groups that I am most interested in studying.

The main themes that arise from these readings are parenthood, recovery and treatment, and bias toward families with a higher income.

**Parenthood**

It is hard to raise even one typical child. Children can often bring a financial burden and take time away from life. With children with autism, parenting is harder; not because of the parents, but because of the way society treats autism. For lower-income, minority race, and immigrant families, views of raising children is different. Some of the issues posited will be mentioned later, but for most families in this population, the children are usually the mother’s responsibility, and sometimes the father isn’t even present. It is the mother who usually has to undergo sacrifices for the child to have a good life, although in a two-parent household, both parents have to make sacrifices. A child with autism, as is seen in interviews and books, sometimes even creates problems in the marriage. This can be because the dad feels inferior, or it can be because the parents no longer have time for each other or they are simply too consumed in the child. At some level, parents even feel helpless that they cannot help their child, and they are desperate to give their child the best life possible. They all want to believe that their child can recover, no matter their background. But other families believe that having a child with autism can lead to divorce, but my interviews showed that this was not the truth. However, parents are afraid, and one parent says, “I’ve heard that 60 per cent of all marriages where there is a disabled child break up. Why do so many marriages disintegrate? Because none of the couples have been told, ‘Beware.’” They have to be told, ‘Look, you’re going to grieve at different times and in
different ways, so you’re going to have to get used to the cycles of grief in each other’” (Bierens, 2009: 104). This is evidence of the impact that autism has on families, how hard it can be to raise a child on the spectrum, and also important in thinking about how families can become stronger through the diagnosis and treatment. Of the three parents I interviewed, two were divorced from their spouses for reasons that they said were somewhat associated with autism, although one parent was still close to his ex-spouse.

When thinking about children with autism, it is extremely important to think about the caretakers and the parents. There are burdens placed on them that are not recognized in this care and there is not much support for them in raising the child. Nussbaum acknowledges these struggles in her book by saying, “these people need many things: recognition that what they are doing is work; assistance, both human and financial; opportunities for rewarding employments and for participation in social and political life...Moreover, much of the work of caring for a dependent is unpaid and is not recognized by the market as work.” (Nussbaum, 100) Parents truly want their children to succeed and drop many of their aspirations to help raise the aspirations of their children. But when raising a child with autism, the definition of success inherently needs to change to fit the mold of what an autistic child may look like. As one author describes, “parents have hopes and aspirations that their child will do well in the world, have friends, enjoy school, adopt a trade or career, and marry and have children of their own. For parents of children with autism, this dream is often replaced with fears and nightmares.” (Hillman et al, 44) However, fears and nightmares are not helpful for the child, and success must be defined one step at a time.

Parents need to start thinking less selfishly about the dreams they have for their children. One parent explained that on the day of his daughter’s diagnosis, a child died. It was, “the
daughter of our hopes and expectations, who would go on to a professional career using what we were sure would be her exceptional intelligence and abilities, who would marry and have children of her own, and with whom we would have endless conversations in which we would share our love of philosophy and life. On the contrary, we learned that Katie would have to defy the odds even to be capable of independent living at any time in her life" (Ariel, 2006: 29). These were his dreams, and not those of his daughter. He learned that he would need to support her and help her through treatment, and love his daughter unconditionally.

Many parents are also often blamed for the development of the child. However, they cannot control everything the child does and they should be seen more as the saviors of the child rather than enemies, or turning their children into brats. Parents can make powerful contributions in the lives of their children. In fact, “parents [are] not only able to learn to be good and effective therapists with their own children – they [are] often more effective than the professionals!” (NIMH, 5) To focus on the mothers, they can be cast out of social situations and treated insignificantly because they are seen as the “cause of [their] child’s disability.” (Cumberland (from Osteen), 184) Yet some mothers, who have the resources, do write memoirs about how they helped their child. Some women are not in that stable of a situation to be able to write memoirs, which is why most come from women of a higher income and white families. Other mothers redefine what it means to be a mother because raising a neurotypical child and a child with disability are extremely different. As Ragone and Twine write, “motherhood is reconstructed by those who nurture children with disabilities” (Ragone and Twine, 2000: 170). They have to rely on other resources and child-rearing practices to raise their children.

For the most part, parents always want their child to lead the best life possible. They all feel weak when they do not believe that they are doing the right thing when they see their child
struggling. As Osteen elaborates, parents are angry at autism itself (Osteen; 2010, 72). This thought tortures the parent because they still feel useless and they realize that they cannot get angry at their child. They want to do anything and everything possible to find the cure. As a parent of a child with autism, he says, “our worst fear was that we’d look back in ten years and say “Oh, I wish we’d tried x.” If we just refused to surrender, just worked hard enough, we’d beat autism.” (Osteen; 2010, 45) Parents simply want to support their child and do not want to miss what could potentially cure their child or help them on the path to recovery, because all parents want their children to be typical. Their hearts drop when they learn that their child has autism, if they even know what autism is. Again, in talking about his child, Osteen says, “with a child like Cam, you can never do enough – never relax, never let up, for fear of overlooking the one therapy that might help or even cure him.” (Osteen; 2010, 86) Parents are not only caretakers. They are also advocates for children with autism and they want to help fund research and help their child get the best treatment possible. They want their children to lead a good life. It is hard to decipher what makes a parent better, whether that is internal or external, or personal versus public.

For our society, it can be hard to believe that non-white, lower-income parents can be good parents since that is not what we see in the media. And for many, that is the truth. There can be a language barrier or a community barrier that is oftentimes not the fault of the parents. For immigrant families, they do not understand the IEPs (individualized education programs) and often have to work multiple jobs and therefore cannot attend meetings at the school regarding the child’s education or therapy (Chipres, 51). The language barrier also creates a challenge in “learning about the disorder and participating in [the] child’s education” (Chipres, 51). Most of these parents had never even heard of autism before.
Recovery, Treatment and Income

There are many limitations to the treatment and potential recovery from autism. The limitations mostly come in the form of race and class.

In order to get the best possible treatment for a child, there must be a good health insurance policy, but there are restrictions on how autism is treated, mostly because some typical members of our society and some therapists believe that autism is a “fake” ailment. As theorist Thomas Szasz, who believes that mental illness is a myth, writes, “children who displease their “behavior raters” are classified as medically ill [justifying] their coerced treatment with drugs” (Szasz, 2009: 20). But for the vast majority, autism is very real. There is no universal treatment or “cure” (NIMH, 1975: 5), but people still want to seek the best possible way to make their child better.

Family life revolves completely around the child. As author Shirley Cohen writes, “autism is the axis around which the family revolves. Jobs are sacrificed, opportunities for advancement are postponed or given up. Families live apart or uproot themselves altogether from their communities to get their autistic children into better treatment programs, to get them a better chance to be cured.” (Cohen, 1998: 64) Again, greatly depending on income and race, many of these statistics change. Some people put all their efforts into raising an autistic child, while other people do not have the resources to even begin to raise their child.

When it comes to schooling, many children with autism would be better at schools that are made for their needs. But in most places in the United States, there are not many schools for autistic children, and of the few that exist, even fewer are of good quality. In the Princeton and Philadelphia area, we are particularly lucky because the tri-state area has a variety of schools and many school districts that can actively participate in helping children with autism and other
special needs. But there are still issues related to income and even being able to send the child to
this school in the first place. Many schools have waiting lists or need to make sure that the child
will fit in, and not all school districts are willing to pay to send the child to the different school.
So when most of the children stay in the regular schools and school districts, parents do not have
much control about how their child will be treated. It is really up to the teacher how much they
can give to the child and how much individualized attention is necessary or possible (Hillman et

This affects how race and class create obstacles for parents. Many parents in
marginalized communities have not heard of autism prior to the diagnosis. For parents who do
not understand English, this is especially difficult because the explanation is hard to understand.
Even for native speakers, they do not really understand autism until they have lived with it.
There are also difficulties in the culture of autism and raising a child in general with any sort of
mental disability. Most cultures, even in the United States as seen before, see children with
disabilities as less than typical people. So although they want to do the best for their child, it is
hard to be motivated when it is rare to cure or recover from autism, and also when it is hard to
get services when the financial situation is not feasible for service. Most people from these
groups also do not really know other families or support groups for parents. Even if they did, it is
hard to attend these meetings because many of these families do not have cars or need to work all
day to support the family in general. They have to attend other lectures that are designed to
become a support group for later on. (Chipres, 45)

To get in a good area to support their child, many families have to relocate. Relocation is
difficult for families, and there isn’t always enough money to be able to relocate. And that
doesn’t always help the child succeed. But relocation is used to help children to go to school and
also to better doctors and therapists. Most of these children do not and could not go to regular
doctor checkups for the first 3 years of their lives. (Chipres, 45) Instead, they are diagnosed later
and do not have the best opportunity to succeed.

John Rawls believes in human equity, and recognizes that our society does not give
people with a lower status the benefit to do well. As he says,

“In a well-ordered society where all citizens’ equal basic rights and liberties and
fair opportunities are secure, the least advantaged are those belonging to the
income class with the lowest expectations. To say that inequalities in income and
wealth are to be arranged for the greatest benefit of the least advantaged simply
means that we are to compare schemes of cooperation by seeing how well of the
least advantaged are under each scheme, and then to select the scheme under
which the least advantaged are better off than they are under any other scheme.”
(Rawls, 2001: 59)

It is unfair to assume that everyone can do well and provide the best possible life for an autistic
child when society is unhelpful in providing. It is not always possible to recover, and there are
many aspects of the country that keep people from having the best life. Without proper income,
or coming from a certain neighborhood, or having the ability to just drop the life you are living
and create a new one is not always possible.

In this thesis, I plan to incorporate these ideas and talk about struggles that caregivers
have when they do not always come from the best backgrounds.

Bias Towards Higher Income

It is unfortunate in our society that there is such a large bias towards families with higher
income. They have access to more resources, and have “better or easier access to other services”
(H, 1/15/13) that low-income families do not have. They also have more of a wealth in time that
they can give to their child and be a co-therapist. Affluent families may also not recognize their privilege in society to be able to access care that lower-income families cannot receive.

One movie, *Finding the Words*, concludes that there are simple and cost-effective solutions (Horn, 2007) to treat and help your child with autism recover. This is coming from higher-class families who also believe in diets and that vaccines create problems, and have the resources to create a scapegoat for their child having autism. Families with higher incomes also “tend to access the more highly skilled professionals and have more direct access to those folks…” (L, 2/28/13) than low-income families who essentially have no access to better therapists. Some low-income families can only afford about an hour of EI once a week, “but that appears to be the extent of service that many children were receiving” (NEILS, 2007: 3-3) and it is also not enough to make a difference in the life of the child.

Programs that are designed for lower-income families may also not have a huge number of families because the families have other concerns. However, when there are programs for higher-income families in more prosperous neighborhoods, there is more participation because these families can afford to participate, in time and finances. As one administrator said, “at my biggest point, I had about 75 people; but with higher income people, I had 300 or 400 people. In my area, we have other commitments and obligations and possibly a job at a particular time” (N, 2/25/13). In the Philadelphia area, there are at least ten programs that I found that focus on families coming from a low-income background or families of different demographics. They are not as well attended as programs for the general population that are mostly attended by higher-income White families; but often, as I (the social worker in Philadelphia) explained, the more focused programs will change names of their lectures to draw as many people in as possible.
I also states that “we also know that what’s available to families drives diagnosis. It helps them get the services and supports that they need” (I, 2/19/13). And because higher-income families can access more services and have more available, they are able to get a better diagnosis and support. In the education system, parents with more income are able to send their children to the best schools and the best teachers. One such school was made so that, “our classrooms are set up so there are individual therapy rooms and a larger room so that they can move back and forth between group activities and individual work” (J, 1/18/13). This works to help children socialize but also have individualized lessons that children with autism need. Parents with more resources can send their children to a school that has more funding and is more specialized for autism. And this is extremely fortunate. While this school offers some grants to children, most of the children are White and from more affluent backgrounds. But this school that works incredibly hard to help treat the children, and really tries to make it fair for everyone to be able to access the school.

It is also easier to put children with autism through school when they have the money. “Upper-class families feel more comfortable going to a school, and lower-income feel more intimidated” (H, 1/15/13). There is intimidation in lower-class families because of the lack of understanding and also the lack of resources mixed with the biases that teachers and administrators have for children with autism. One therapist, E, described this situation very well. She iterates, “I work with a lot of high-income families and they are very fortunate because they can get unbelievable resources and can spend thousands of dollars on world-renowned therapists…I have families from here who can’t even get into CHOP who are on the waiting list for 2 years” She also says, in terms of the Therapeutic Support Staff (TSS) support, that “a lot of the parents of lower income, if they have an impaired child, they can get the TSS support but the quality is very poor. If you’re affluent, you can hire someone yourself who is well-trained” (E,
2/22/13). In schools and districts, such as the Philadelphia School District, TSS support does not have priority for funding, and they lack the resources to serve children with autism in the best way. Families who are more fortunate can hire someone who can support the child individually.

**Methodology**

*This study was approved by the Swarthmore College Institutional Review Board.*

When working with anyone who has a role on the autism spectrum, there are ethical questions that come into play. There are certain questions that I cannot ask, and I need to be sensitive to their needs and their limitations. I also need to balance compassion and empathy so as not to sound demeaning. In this project, I take an anthropological perspective upon the struggles of caregivers working with children with autism. There are many emotional and physical struggles, as well as struggles in their career and home that are forgotten about because of the perspectives surrounding autism and the stigma that our society places on autistic children. So I will show those stories through an analysis of their relationships with the children. With this thesis, I plan on giving caregivers ideas to best help their children with autism.

**Initial Thoughts**

Before starting on this project, I thought it would be very similar to the work I was doing with the children I worked with in the past. But there are many stigmas attached to autism that are not attached to other mental disabilities. Of course, there are similarities between children with autism and other disabilities. For example, they are not seen as full citizens and there are
still battles about providing the best care for the children, whether it means insuring their appointments and medications or giving them the best education possible.

However, when I entered this project, I didn’t know much about how pervasive the issue of autism, health care access and socioeconomic status was. And related to the huge spectrum of autism, I felt as if some parents could see it as possible to over-diagnose or over-treat children with autism and not receive enough support in the health care system. I also had no idea how many issues there were with autism that are not relevant with other disabilities. For example, autism is not taken as seriously because it is not a disability that is visible to the eye, as I said earlier in my thesis. Therefore, it is not as credible and not given as much support as it needs.

I also went in thinking that it would be fairly easy to find people to interview and I was just trying to find anyone who had any relationship with autism whatsoever without really knowing what I was looking to find out. I also thought that with asking questions, I was going to raise a lot of sensitive issues, which is still the case, but I did not think that talking could be a relief for some caregivers.

And because I worked with schizophrenic and bipolar children before, including my own cousin, I was able to be empathetic towards their needs and expressed that this was entirely voluntary if they did not want to continue.

I wanted to work specifically with parents, counselors, teachers and other caregivers because I felt that their struggles were often forgotten about. There is also a difference in the way they work with the kids, and when we try to figure out what is the best policy to take, we need to consider all the ways that they have already been working with the children. They also have different perspectives of what autism is and the symptoms, and therefore formulate their methods around those ideas.
Ultimately, although I interviewed a wide variety of people, I mostly focused on getting research on the parents in relationship to the children and also what social workers, therapists, program coordinators, teachers, and psychiatrists would see.

I also learned that I would need to change my vocabulary to talk to people who work with children with autism. For one, autism is not the identifying factor of children, and I learned that, even though I do not see autism as the defining feature, it is respectful to say “children with autism.” I also went into my first interview asking the father of a son with autism about his son being seen as “normal.” He automatically corrected me saying “typical.”

Informants and Interviews

One of the main parts to conducting research for my thesis was by performing interviews. I interviewed 3 general groups that included parents, teachers, and counselors. That made classification easier and also helped divide up my questions since I had specific questions for different groups.

I found them in different ways. I knew some parents and teachers and they were the first people I interviewed. But many parents know other parents of autistic children because of support groups or other types of resources. Those parents and teachers would then direct me to other people who could help, virtually a snowball sampling.

Another way was by finding people and groups online and I would contact people specifically rather than through organizations. This means that if I contacted other parents, it would be from them personally giving me their contact information or through support groups. With teachers, I found them through parents and not through the principals. Directories on the websites were helpful to find teachers. When I contacted therapists, I would either interview the
person in charge or find people more suited towards my project on the website and by doing searches for therapists who specialized in autism care in the Philadelphia area.

Parents did not have to worry about me reaching out to the schools or think that the school would know that they said anything. I would not use any descriptors that were specific to the school. There were also various schools and centers in the Philadelphia and Princeton area where I conducted my research so that it would not be completely obvious to tell where my research was performed and with whom.

I also assured confidentiality and gave everyone I interviewed consent forms. The two ways I found people to interview were also important for confidentiality because only they knew that I was contacting them and we were in private spaces during the interview.

Interviews were generally conducted in an intermediate location where we could speak privately, in their offices, or in their living spaces. I let them choose where they wanted to meet so that we could be in the best location for them.

In total, I performed fourteen interviews with a variety of people. Unfortunately, many people who I wanted to talk to were not available, did not answer me, or we could not find a time to meet.

My informants were extremely diverse. In retrospect, I would have been better off if everyone I wanted to interview responded to me, but many of the immigrant parents and parents of racial minority backgrounds were more hesitant to go through the interview process. However, I had one mother from the United Kingdom whose daughter's story opens the thesis, a father of an African-American background who also started a program for families in his community, and various other individuals who have played an important role in research or by being parents.
Location

I conducted my interviews in Princeton, New Jersey and Philadelphia, Pennsylvania. I originally expected this to be a more national project, but my readings and settings mostly focused on those two general areas. I realized that to fit this for the country would be an impossible exploit as every state has different resources, and in these areas, families have more resources. Although both states deal with autism differently, the people who live in these areas are much luckier than families living in other areas that have different regulations, or where the closest specialized school or therapist might be 100 miles away.

Research: Books and Setting

Autism is a relatively new disorder when compared to other disorders. The contemporary nature of autism could lead to the opinion of many people that autism is made up, and is not seen as important and therefore it is not necessary to provide treatment or equal access to healthcare. There is more research that has been done related to autism in recent years that questions past speculations. There are new treatments and new ways to train psychiatrists and counselors about autism. There is no cure and no way to end the symptoms. We’ve moved far from when doctors believed that children had hearing problems and behavioral problems that they thought the children would simply grow out of. We now know that the children cannot grow out of certain behavioral problems.

Then I started to focus on clinical perspectives, parental perspectives, and the different teaching mechanisms as a basis for what I was going to research. From there, new ideas appeared related to citizenship and disability rights; different economic, domestic, and emotional
struggles; and what treatments were working and benefiting the children. In autism, another important idea is to focus on the individuality of people on the spectrum.

Plus the reading, I also took preparations in conducting my interviews. I would use the readings as a basis for my questions and then have more open-ended questions that I could relate back to a book or article. I was also sensitive about the time and their privacy of my interviewees, so I conducted my interviews in a place where they felt comfortable. This included mostly coffee shops and offices. This also meant that if I needed to have an interview by the phone, I would do so. If we could meet in person in a closed space, I would try to do that instead. But sometimes they would not be able to meet or had other plans.

Methods of Gathering Data

I used a variety of ways to gather data and to find the research that I needed in order to write my thesis. The first, which I mentioned before, were the two ways in which I found people to interview. Using those ways, I was able to keep the conversation more personal and comfortable, and I found that the people I talked to really enjoyed talking to me. They also seemed to feel a sense of relief after talking because, especially for parents, not many people are willing to listen as intently. I used a wide variety of primary and secondary sources.

Blogs were also an important part of my research in the beginning. When I wasn’t sure about the stance I would take, I found several useful blogs for my project where parents talked about the struggles of their children or talked about their own struggles. They were all very personal, and it is also useful to read the comments section where other parents and related people talk about the issues that they’re having and how society has impacted their lives in this sector. Many blogs share very personal stories about what is happening in the lives of the
children, or the relationship they have with teachers and counselors, but some also provide an analysis about their child which correlates to some of my questions and has provided a basis for some conversations I’ve had during interviews. However, most blogs were written by higher-income, White families. And this is part of our societal structure where it is easier for higher-income people to talk about disability but also in their access to computers and education.

I also asked different people about going to support groups, and I obtained mostly positive responses. Support groups are found in two basic structures: the online support group and in different centers. The online network is specifically only to provide a space for support, while in person, the centers are not just there to be a support system. Many of these centers also offer treatment and counseling support, or treatments for the children in the form of music, art, and counseling. I mostly relied on the support groups that were in person. I was fortunate enough to be able to attend and meet parents, but also be welcomed into their lectures. Although I did not record these families, many of them willingly spoke to me, introduced me to their children, and allowed me to be a part of their life. Through these support groups, I was also able to talk to other people who could help me in my research.

Online support systems have been beneficial for families for a variety of reasons. These systems are free of charge after parents are already spending large sums of money on treatment and education, but they’re also possible because it does not require parents to find babysitters and it is already not possible for some parents to have jobs because they need to raise their children. Raising autistic children is difficult, and parents try to spend as much time as possible with their child. This is why the internet is such a fascinating realm because parents get resources and support.
I also relied extensively on secondary source books and articles. There was a wide variety of books available to me in my search, all of which were helpful in understanding and investigating childhood autism. I divided these books and articles into three separate categories. The first is personal narratives of parents and people with autism. The second is guides and documents, which also includes government documents, books about symptoms and types of disorders, clinical guides, and ways in which we treat autism. The third is books from theorists such as Foucault, Goffman, Rawls and Nussbaum. They discuss punishment, mental disorders, stigma, and how we see disabled as citizens or not. With articles, I was extremely lucky that so much of the research was and is based in the Philadelphia area. I could personally contact many of these researchers and meet them to understand more about their research.

These methods were all extremely helpful in completing my research because they helped add to what I had or helped me to formulate new theories as to what could be and wouldn't be helpful.

**Personal Reactions and Biases**

Ultimately, my thesis became very based on the parents. They needed to constantly be there for the children, had to continue the teaching at home, and they were the ones who had to transform their lives to help their children. In terms of my own research, there was not as much done by the teachers and counselors, except for when it came to clinical guides and different books about treatments that counselors were using.

And when thinking about the experts, the people who end up caring more about autism and writing about autism are the parents who become experts. They need to figure out the best
treatment, put their children in the best schools, and also deal with the ups and downs of the lives of their children.

In many ways, I had to question my own ethics and I am still questioning myself if I have said the right things to portray the lives and give justice to the children, families and to the other caregivers who put in so much of their energy into bringing autism to light.
Works Cited

Interviews

Books
Adams, Christina

Barnbaum, Deborah R

Bérubé, Michael
1996  Life As We Know It: A Father, a Family, and an Exceptional Child. New York: Pantheon Books.

Bierens, Francesca.

Cohen, Shirley

Foucault, Michel

Goffman, Erving

Greenspan, Stanley I.

Hillman, Jennifer with Stephen Snyder and James A. Neubrander
Rawls, John

National Institute of Mental Health.
1975 Parent—Child Program Series Report No. 3 Parents as Cotherapists With Autistic Children by the National Institute of Mental Health from the US Department of Health, Education and Welfare

Osteen, Mark

Osteen, Mark, ed.

Phillips, Sarah D.

Sargent, Carolyn F. and Thomas M. Johnson, eds.

Szasz, Thomas

Articles

Sharpe, Deanna and Dana Lee Baker.

Solomon, Olga
Chapter 1 – Perspectives on Autism

Disability is often hard for people in our society to understand, and is devalued by various members of the community who do not see differently abled people as priceless. Anthropologists Rapp and Ginsburg claim that disability is a social construction (Rapp and Ginsburg, 2012: 169) and as a society, we are the ones limiting people with disability. But they further add that disability is an “essential form of human diversity” (Rapp and Ginsburg, 2012: 182). Ability is necessarily an aspect of a person’s identity. Therefore, to put a price on a person with a disability such as autism is devaluing a member of our community. People with disabilities such as autism, “are compelling us daily to determine what kind of “individuality” we will value, on what terms, and why. Perhaps those of us who can understand this intersection have an obligation to “represent” the children who can’t; perhaps we have an obligation to inform the traffic about our children” (Berube, 1998: xix). We have an obligation to ensure the pricelessness of children with autism who play a role in our community as individuals.

In this chapter, I will be first discussing the initial reactions that parents have to their child’s autism diagnosis. Many parents are devastated, and therapists work with them in the initial feelings. Then, there is a stage when parents believe that they did something wrong, and I focus on their guilt. Last, I talk about bullying and abuse, both of children and their parents.

What are the initial reactions to Autism?

Many parents get the diagnosis of autism and have no idea what autism is, or know much about the diagnosis of autism and how much it will affect their life. Autism can range from not giving eye contact to having a “projectile vomiter” (L, 2/28/13). L is a psychiatrist serving children with autism. However, there is no magic cure for autism, even though people often
believe that there is a cure for everything. Treatment is always better, though, when parents get
diagnosis earlier.

For many parents, hearing that their child has autism was “one of the worst days ever” (F,
1/11/13). From what we see related to autism as a society, autism seems like the end of the
world. Parents have dreams for their children, and those dreams seem to go away with a
diagnosis of autism. “We have dreams for the future, but they’re different dreams, because every
day...something happens to remind us of reality” (Ariel, 2006: 38). Parents are constantly
reminded by the people around them that their child is not a typical child, and that their dreams
for their child are not always possible to achieve. And this is not only the perception of parents.
In the media, autism is also portrayed under a negative light. “How autism is seen in the media
and on film is very important in how the autistic population as a whole is viewed, understood,
and treated by lay persons and professionals alike...film portrays have so far exhibited characters
with autism as mentally defective, abnormal...freaks, rejected by their families, sent away as
children to institutions of some kind and with an obvious lack of care, love and respect afforded
to normal human beings” (Waltz, 2005: 432). Although sometimes the media will diminish and
turn autism into a cheerful disorder, the media also reverses this sentiment by portraying people
with autism as less than human, as people without feeling, and as people go through life without
respect from society.

Most parents learn that raising a child with autism will essentially be a full-time job,
which not many families can do, especially with the low-income group that I focus on because
they already have several jobs. One social worker explains, “we sit down with the family to
understand what these things really mean and what they really are to understand what will be
actually worked on and why 40 hours a week won’t really do much” (M, 1/15/13). And with the
40 hours already not being enough, these families become discouraged and need to figure out ways to help their children. They simply refuse to work with their children this long – not because they do not care, but because there are other issues. They just want a fast way to make their children better. They look for “magical explanations” as to why autism struck their family (Osteen, 2010: 110). And then they learn that there is “no established bible to treat” children with autism (I, 2/19/13).

Am I a Bad Parent?

Many parents of children with autism question whether or not they are bad parents. They wonder if they did something wrong to have a child with autism, or if they’re doing enough and searching for the best treatment to raise their child. In the minds of many parents, “autism has become this plague that is taking over children and it’s destroying lives, but that’s not the case. [Parents] internalize [autism] as something that is wrong with them that snowballs into depression” (L, 2/28/13). They are blamed for their children acting out, and they always feel like they did or are doing something wrong. Many of the mothers didn’t know about disabilities until they had their children. There are feelings of fear and of doing something wrong (Skinner et al, 1999: 491). Parents though are mostly angry at autism – they don’t know what to do, they don’t understand what is wrong, and they want the best for their child to lead a healthy, good life. Parents are desperate to help their child, particularly if they are low-income and do not have the time. They recognize that their situation may not always be the best for their child either. And many people don’t recognize the parents of the children and how autism affects their lives.

Autism has a huge effect on how families bond with each other. “Many parent narratives actually have coping with this ‘spoiled social identity’ at their core, placing the person with
autism in a secondary position within the narrative” (Waltz, 2005: 428). Although this is not the best way to interpret the way in which parents can truly feel, it is true that parents have learn how to “cope” because their child isn’t as they imagined, and has an identity that they are not comfortable with. Families are always undergoing sacrifices so that their child will have a good life. Sometimes, “one or both parents often must reduce work hours or step out of the labor market altogether” (Sharpe, 2007: 248) in order to take care of the child. Many low-income families are also single-mother households, so rather than dropping a job, they have to pick up more jobs to pay for the expenses of their child, and cannot always be there for their child. Other members of the family also may not accept the child, particularly in Latino families where Catholicism often plays a large role in community building. The family members will frequently believe that the mother sinned in some way to have a child with a disability, according to researchers and people I interviewed. There is a “belief that children with disabilities are sent to parents as a punishment for some sin they have committed” (Skinner et al, 1999: 488). The family might see the child as a punishment, not necessarily the mother. The family sees that the mother deserves to feel this pain, and in this way the social ties to the cultural perspectives. Families put a lot of pressure on the parents and put a lot of fault on them for being bad people and bad parents, which is why the child ended up having a disability.

Even some parents have a tendency to “other” their children when they are not acting typically. One author, Bettelheim, is one of the first biographers to document his own son’s autism and blame it on the parents. He completely “others” his son in the representation (Waltz, 2005: 425) and is not willing to accept the differences. Some parents also “don’t tend to take the kids places sometimes because they may make loud noises so they become more isolated” (J, 1/18/13). J has this experience serving as an executive for a school in New Jersey and working
directly with children and parents each day. When people from the community see parents and children, they immediately judge without considering that there is a reason behind the child acting out. As one mother of a 10-year-old with autism notes, “casual people who might observe in public might not understand why he’s acting the way he’s acting” (D, 10/25/12). Of course, she feels awful that she cannot always take her child out, but there is bad feeling that comes towards families who have a child with autism. Another parent narrated that, “The other parents’ attitudes were the hardest thing about having a child with autism. I used to see these parents standing there, staring and often criticizing. That was really hard” (Bierens, 2009: 46).

But with the support of clinicians and outsiders, most parents learn that they are not at fault for the child’s autism. As one parent and director of a program for children with autism and their parents notes, “I have to be reminded by my friends that it is hard, and he is my child…” (N, 2/25/13). He relies on his support system to recognize that he is not to blame, and that he can help his child become better. And it is hard to raise a child with autism, but he needs to be ready to undertake the task no matter what the emotional toils are. And therapists must also “respond in ways that are adequate for the kids and evaluate the way in which the child lives” (L, 2/28/13). Therapists are beginning to work with parents and help them change the way in which the child lives and also help the parents.

Many parents are learning to change the way in which they look at their children. They start to recognize their sacrifices, and “as parents listen to others’ stories of disability and learn to tell their own, they actively make sense of what this event means for themselves and their lives. Their stories may change, in fact are likely to change, as they encounter new experiences and people, and tell their stories to different audiences” (Skinner et al, 1999: 483). Their children are their little angels, and by taking this perspective, they can also validate the sacrifices they have
made for the child. They also start to see themselves as special parents as a way of health, and also as a way to control their emotions (Skinner et al, 1999: 489). In this way, they become stronger and are more ready to help their children, and have the necessary support to see that they are not bad parents. One author, Clara Claiborne Park “eventually decides that what [her daughter] needs most is respect for her personal integrity, support for her special talents and assistance with those tasks she finds difficult” (Waltz, 2005: 429). She wants to build respect for her daughter, and show people that her daughter is special and through a biography, show that she is also a good parent and is working hard to get the best help for her child. Parents learn how to take their children to public spheres that were once not navigable and how to make them feel more comfortable, but also learn ways to work with their children’s fears. G would take her daughter to the movie theater thirty minutes before opening so that her daughter could get used to the space before people came in. J explained that as part of her program, she takes children out so that they can understand social spaces and become more independent.

Various therapists are learning how to support parents in the most efficient way so that they are not only helping to treat the children, but also to change the mindset of parents who are struggling to raise their children. As one social worker in Philadelphia told me at the end of our interview, “see, we’re cheerleaders” (H, 1/15/13). We must be cheerleaders for the parents so that they can see their potential as good parents.

Bullying and Abuse

Both the parents and the children with autism are likely to be bullied and abused by other members of society. Kids who are also of color are generally more likely to be bullied. Parents
are seen as bad parents because outsiders think that the child is just a natural brat. Children who are of color are also already more likely to be bullied at school and in society.

Even if children are not being bullied, they are constantly made fun of. As one parent notes, her daughter was, "made fun of more than being bullied. And teased and just...people not wanting to be with her and not wanting to give her a chance" (G, 1/12/13). It was always hard for her to see her child constantly tormented by her peers, just as it is hard for any parent. Now, her daughter is in a center that specializes in working with autistic children. Although the mother feels guilty, she knows that it is the best option for her daughter to not be treated badly. However, the same mother also notes that the hospital is a manipulative place, and she feels like she is bullied by the hospital herself and does not always know what is happening to her daughter. While her daughter is a completely different person now who is almost a zombie wandering the halls, "If I say no, I don’t know how they would treat my daughter" (G, 1/12/13). Saying no could put her child in a vulnerable situation, or it could also lead to her child being kicked out of the facility.

Even a researcher notes that in some hospitals, there is “bullying of families and parents, and not just the kid with autism that we have to worry about” (I, 2/19/13). Parents are always pushed to do more than they can, and when they cannot put in all of the necessary effort, hospitals try to pull every penny out of them and make them feel bad for not being able to help their child more. When it comes to society, “the mother of a disabled child may be damned by society because she is perceived as the cause of her child’s disability” (Cumberland, 2008: 184). The mother is pushed into the limits of society because she is always blamed and punished for having a child with autism. It is not surprising that, “most mothers at least initially assum[ed] that they personally must have done something wrong to account for the disability” (Ragone and
The way that society often treats most mothers with children with autism can lead to much guilt.

Social workers have to help parents to show them that they are not at fault and not listen to what people are telling them so that they do not feel guilty for causing autism. As one social worker says, “we tell families to have a filter and take their time and not get discouraged from things they hear from other people…” (M, 1/15/13). They try to teach parents not to listen to what other people are saying about their children and about them, and to keep trying to work with their children because it is not their fault. And the social workers want to be able to give the families as much support as possible or necessary so that they do not become demotivated.

But then there is the problem of bullying the children. Although I will touch on this more for people of lower socio-economic backgrounds, it is important to note that bullying is extremely common for all children with autism. People with autism feel that society disables them because their “rationality is questioned” and they are not seen as living in a reality (Waltz, 2005: 431). One case that a therapist told me about was that her patient was being abused by his mentor, and even though she testified as an expert witness, the organization was able to pay more for the case and the lawyer was able to testify against the child’s rationality. The child for once opened up about this awful situation, and then no one believed him. It was a lose-lose situation, that also goes to show how society views children with autism as not rational and pushed to the margins.

People with disabilities are seen as freaks and “the voices and views of people with disabilities are heard (or not heard) within these narratives,” which constructs and perpetuates views of disability held by our society (Waltz, 2005: 422). Children with disability are constantly
oppressed in this society (Hughes, 1999: 167). Cases like these are a reminder that our society is afraid of disability, and bullying and abuse come out of this fear.
Works Cited

Interviews


Articles

Harry, Beth with Robert Rueda and Maya Kalyanpur.

Hughes, Bill.

Rapp, Rayna and Faye Ginsburg.

Sharpe, Deanna and Dana Lee Baker.

Skinner, Debra with Donald Bailey, Vivian Correa, and Patricia Rodriguez.

Waltz, Mitzi.

Welterlin, Aurelie and Robert H. Larue.

Books
Cumberland, Debra

Landsman, Gail.

Osteen, Mark

Whiffen, Leeann
Chapter 2 – The Ethics of Autism

How do we define a human as worthy? What makes someone a citizen? When positing these questions, we often forget about the disabled community and if we are treating people with mental and physical disabilities with the same ethics and positions of citizenship as we treat a typical person.

When it comes to moral philosophies, there is a level of empathy that must be evident to at least begin to respect an individual with disabilities as an individual who deserves equal rights. This empathy cannot demoralize or undermine people with disabilities. As author Mark Osteen writes,

“How do we carry on these mediated dialogues and still respect the agency of those with whom and for whom we speak? Clearly we need empathy, which legal philosopher Martha Nussbaum defines as the “imaginative reconstruction of another’s experience, without any particular evaluation of that experience”…The distinction [between compassion and empathy] is significant…because compassion may go hand in hand with a feeling of superiority…that even severely disabled people rightly resent as patronizing. Compassion, that is, can easily lead to colonization.” (Osteen, 8)

When it comes to disability, the assumption is that people are only really worthy of a better life if they can overcome the disability. Especially with autism, because there is no distinguishing feature and children with autism look typical, there are higher expectations for a recovery process and to act like a typical child. And with a media reflection on autism, people with autism are diminished of their uniqueness and differences in how autism is identified. In this way, although people are trying to care about how we as a society have failed children with autism, their compassion is also not helpful towards supporting the child because they assume that all children will react in the same ways. Osteen also expresses this in saying that, “Such
representations may be compassionate, but in failing to respect difference, they are not truly empathetic.” (Osteen, 8)

Especially with education, there is the difficult expectation that children with autism are “gifted,” and should be placed in regular classes, or they will be placed in special needs classes and often not given the attention that they need to succeed, and their placement is questioned. Unfortunately, in the public school system where many low-income children are placed, schools are not required to give better treatment to autistic children (Hillman et al, 120). One philosopher, Martha Nussbaum, says that, “an especially egregious gap has been in the area of education. Stigmatized as either ineducable or not worth the expertise, children with mental disabilities have been denied access to suitable education.” (Nussbaum, 200) Nussbaum focuses on the citizenship of people with mental impairments, and part of her research relies heavily on educational background where she recognizes the gap between typical and mentally impaired children. She also agrees with Hillman in the sense that school systems do not give or do not necessarily care to give children with autism the best education possible. Rather than educating children, they simply try to teach children how to be more “normal.” School systems single out children with mental disabilities and say that their education needs to be “individualized and aimed at fostering human capabilities” (Nussbaum, 209). And again, children with autism do not look different so teachers expect autistic children to act typical. As Nussbaum argues, “…it is difficult for children and even teachers to believe that someone who can think [so cognitively] has a disability. They find it easier to believe that he has a bad character and/or bad parents” (Nussbaum, 207).

Education and citizenship are tied together in the ways in which we educate people with mental differences and people with regular ability. So even if a child is a citizen according to
law, he will be treated as if he is of lower status because of the way our school systems define his status as a citizen. They reject responsibility. However, society must take into account these issues that people with mental disabilities and autism especially have in caring for all citizens. “Any decent society must address their needs for care, education, self-respect, activity and friendship. Social contract theories, however, imagine the contracting agents who design the basic structure of society as “free, equal, and independent,” the citizens whose interests they represent as “fully cooperating members of society over a complete life.” They also often imagine them as characterized by a rather idealized rationality. Such approaches do not do well, even with severe cases of physical impairment and disability. It is clear, however, that such theories must handle severe mental impairments and related disabilities as an afterthought, after the basic institutions of society are already designed. Thus, in effect, people with mental impairments are not among those for whom and in reciprocity with whom society’s basic institutions are structured” (Nussbaum, 98). Nussbaum also quotes Rawls quite frequently as someone whom she was able to structure ideas around, and John Rawls tends to support her. As he writes, “in securing the equal basic rights, liberties and fair opportunities, political society guarantees persons public recognition of their status as free and equal.” (Rawls, 2001: 200) The difference is that he does not recognize that there is no public recognition of their status as free and equal.

Other theorists, such as Erving Goffman, discuss the idea of stigma in relationship to disability. As he claims, “the attitudes we normals have toward a person stigma, and the actions we take in regard to him, are well known, since these responses are what benevolent social action is designed to soften and ameliorate. By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through
which we effectively, if often unthinkingly, reduce his life chances" (Goffman, 5). We often treat people with disabilities, and children with autism, as if they are in control of their situation. We expect that they are not truly on our normalized level of lifestyle, but we desperately seek that normativity. They are almost treated like criminals who don’t understand the crime. As Foucault elaborates on, society defines “what must be regarded as a crime: it is not therefore natural” (Foucault, 104). In this sense, we must also question how people can punish an autistic child who does and will not understand the crime.

If we don’t consider autists as members of the moral community, then we also forget about the moral weight we owe them and we mistreat them as individuals and exclude them from benefits of society. If we make conclusions about who is a member of a moral community and we are wrong, then the costs are really high.

When it comes to low-income families, there are various ethical situations that come into question because society does not take care of low-income people in a fair way. There are many questions that we need to ask ourselves when it comes to how we must treat everyone in a just and fair way.

Autism is an extremely controversial field. There are always new decisions and new information coming out about autism, and the people who have autism are always pushed to the fringes and do not have a say in the decisions being made about autism. Their citizenship is questioned, especially as low-income children and children of color, people are manipulated, and they lose trust in the system. And especially now, “there is a big push to diagnose children early and for some of those children who may have some but not enough of the characteristics [of autism]...it is great if it is correct to diagnose early but...the label hangs with them and that could be a detriment...” (A, 2/28/13). A is a teacher for children with autism in Philadelphia.
The label of autism is bad enough and “parents may push for their children not to be labeled” (A, 2/28/13). Children do not benefit from not receiving a label for autism.

“disability diminishes personhood” (Ragone and Twine, 2000: 169)

**Citizenship**

Children with autism are not seen as moral members of the community because they cannot always think for themselves and are not seen as making rational decisions. As Erving Goffman wrote, “by definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances” (Goffman, 1963: 5). Although this book is outdated in the sense that theorists have different perspectives fifty years later, it is true that we often see children with autism, and anyone with a disability, as less than human. And therefore, we discriminate against them and do not see them as members of our moral community. Parents are actively defiant against this perception. One said to me, “I can be his father. But I’m not going to be his trainer” (F, 1/11/13). The therapists wanted him to train his son as if he was an animal, but he resisted and his son ultimately did better.

Children with autism are removed of their citizenship, especially. With regards to autism, there is no real physical difference between people with autism and typical people. However, children with autism can’t necessarily make their own decisions about what is best for them, even if they want to (Nussbaum, 2006: 185). In this way, we’re removing them of their citizenship. This is the same way we also remove low-income and multicultural children of their citizenship and questioning the role that they play in our society.
Some schools and educators also take away the citizenship of the students. Although schools are legally obligated to provide the best service available to children with disabilities, "stigmatized as either ineducable or not worth the expertise, children with mental disabilities have been denied access to suitable education" (Nussbaum, 2006: 200). It is a rule that many districts get around and therefore schools are not required to give better treatment to autistic children (Hillman et al, 2007: 120). They simply get around the law, and do not treat children as well as they should. The way that they get around this is by saying that children with mental disabilities must have an education that also needs to be "individualized and aimed at fostering human capabilities" (Nussbaum, 2006: 209). So rather than really providing an education, they do the minimum to "teach" a child how to adapt to society. This goes to show that children with autism don't get the best education possible, and especially lower-income children who cannot afford to get better education and have to accept what the school gives them.

As E said, describing the beginning of her career as a teacher, "when I first started teaching, no one knew about autism. People were resistant to my kids, and I had to work to make sure my kids were accepted...my biggest frustration is the inequality in the school system. They are treated as second class citizens" (E, 2/22/13). Even Therapeutic Staff Support (TSS) is not always there to support the kids (L, 2/28/13). Children with autism are treated as second class citizens and are not given the support that they need by their schools to prosper and do well. Institutions, such as our academic institutions, are not structured to make lives easier for people with mental disabilities. As Nussbaum writes, "in effect, people with mental impairments are not among those for whom and in reciprocity with whom society's basic institutions are structured" (Nussbaum, 2006: 98). They are not treated in the same way as typical students, and school districts are not willing to cooperate in making the lives of these kids easier.
In many ways, we take an unethical stance and remove people with disabilities from our moral community. If we don’t consider autists as members of the moral community, then we also forget about the moral weight we owe them and we mistreat them as individuals and exclude them from benefits of society. If we make conclusions about who is a member of a moral community and we are wrong, then the costs are really high. For members of the community and of society, being a member of the moral community really means being able to play an active role and being able to think completely rationally at all levels. Yet, this limits us in our morals and keeps us from recognizing the many people with disabilities in our society.

“Nussbaum...states explicitly that the failure of an individual to be “fully human” does not demonstrate anything about what is owed to that individual...it is possible not to be regarded as fully human, and yet still be an individual to whom we owe moral obligations” (Barnbaum, 2008: 83). Because we have a strict definition of humanizing other people, we cannot treat people with disabilities as part of our community. In thinking about this, some aspects of citizenship are more important than others, and we must protect those important roles for people with mental disabilities.

Punishment

In our society, we almost treat disability as if it is a crime. While the citizenship of people with autism is questioned, we also see autism as punishable. Although the treatment is not called punishment, it is inhumane and a way in which we would not treat another child and would probably treat a criminal. Children with autism are often constrained, shocked, and put into solitary confinement for long periods of time. Especially at the Judge Rotenberg Center and in some public schools, children have been put into bags, or locked away. The Judge Rotenberg
Center claims that this is helpful for the child. As Foucault says, "it is true that society defines, in terms of its own interests, what must be regarded as a crime: it is not therefore natural" (Foucault, 1977: 104). His argument is that disciplinary punishment is the best way to educate and teach, but for children with autism, it is impossible to teach by disciplinary punishment. And as moral members of our community, we have to wonder how it is possible to punish an autistic child who does not understand their crime.

One institution for children with autism, the Judge Rotenberg Center in Massachusetts, has been known to shock children who do not listen to the rules. As one article exclaims, "in some cases, [the kids] are shocked as often as 30 times a day as a means of dissuading them from behavior deemed dangerous to themselves or others" (Pilkington, 2011). However, many times these behaviors are not dangerous to anyone. There is a video of a boy of color who is shocked nearly to death because he did not want to take his coat off (YouTube, 2012). Yet, it is not illegal. Shocking is extreme and can be deadly, and it happens more to children of color. It should be illegal to harm children and disabled children in this country.

Less extreme is the issue of solitary rooms. One ABA therapist, C, brought up the fact that some parents think that they should be illegal, but other practitioners see them as a benefit because they keep other children, and also the child in the room, safe. However, D wrote in the IEP for her son that she does not want him to be going into the restraint rooms at the schools. There are many horror stories of children who are put into these rooms or put in bags and punished by teachers and therapists in radical ways that also do not teach the child what they did wrong.

I am not sure how disproportionate punishment is amongst race and class distinctions, however, for parents who do not understand the Individualized Education Program (IEP), they
cannot say that they do not want to inject their children with anesthetics or to not put their child into restraint rooms.

**Guilt**

One of the many things I learned from doing these interviews is that all people who work with children with autism feel guilt and anger for not being able to do everything for their children, knowing that the anger and frustration will do nothing to help the child. One of the biggest points made by all parents was that “our worst fear was that we’d look back in ten years and say “Oh, I wish we’d tried x.” If we just refused to surrender, just worked hard enough, we’d beat autism” (Osteen, 2010: 45). However, this is not entirely possible. So coping with that, other parents have said, “you feel guilt…and inadequacy and you couldn’t feel like there was anything you can do” (G, 1/12/13). Or that the child does not get invited to birthday parties or playdates anymore, as D reflects. D continues that “they’re accepting of him in context of school…and he’s young enough to not know when he is bullied yet” (D, 10/25/12). Parents may also feel guilty that the child “doesn’t always understand…he would just go on and on about when he would be coming back over…[and] I feel guilty that he doesn’t have friends” (N, 2/25/13). Parents hate to see their child struggling and do not feel like they are doing the right thing when they see this reflected in their child.

Many therapists also feel guilt. One challenge is continuing “to work with families even if you think they’re doing potentially harmful things with the hope of steering them away” (B, 2/15/13). Oftentimes, they know that the family may not come back. They want to help the children, and parents can make it difficult. Other therapists feel guilty when they “hear a story about the system failing someone…there are stories about parents talking about removing carpet
and removing heavy metals and kids who have died from therapy...so when you hear those stories you would wish you could help that family” (I, 2/19/13). I researches autism spectrum disorders. Therapists feel like they always have to be there for the families and the children. There is also the guilt that “there is always something more that you want to do...there is a constant struggle and this is why people might burn out...it kind of ends up eating you” (A, 2/28/13). Therapists and people involved always want to do more to help the child, and they know that they cannot always do what they want to do or what they feel is right. Then there are the workers who realize that the institutions are not always doing the best for the child. “I feel guilty when I can’t give a parent the comfort that they want...when they ask ‘will my child get better or get married’ and I can’t answer. And ethically we can’t say ‘your child is getting bad help...’” (H, 1/15/13). A lot of parents get “screwed” by agencies, and the agencies recognize this.

**Manipulation and Trust**

As one therapist noted, many parents are being manipulated by hospitals and organizations. They take advantage of the parents and children, and as G said, they overmedicated her child and do not give her an option in the care of her child. Self-help books, written by upper-class White women like Jenny McCarthy, also take advantage of people by giving false advice, unscientifically “proven” anecdotes and treatments, and are especially bad for low-income mother who cannot always read these self-help books and hear this advice by the therapists around them, or listen to what they said because they do not have a support network. They will also listen to what they are told because they do not have the time to read or understand.
As I says, “treatment groups try to sell to parents that their children may recover...but “recovery” can also manipulate...if you just pay me thousands of dollars [your child] can recover” (I, 2/19/13). Hospitals try to sell these treatments to parents who do not understand much about autism, especially low-income parents who are more vulnerable. And parents will listen because they are “using different agencies to *fix* the problem...it’s a career they didn’t sign up for. [Some] hospitals perpetuate it too…” (H, 1/15/13). It’s painful for parents to learn to accept their child’s autism, or have been doing the same thing for a long time and just don’t want to deal with it because they don’t have the time or resources and will try to scrape up the funds to make it possible to heal their children. Parents recognize the awful treatment of the hospitals, but because they want their child to be given the best treatment, they will continue to utilize them. Manipulation is not ethical, and also removes the children and the parents of their citizenship when their choices are ignored or they are simply not given choices.

Bullying and Abuse

The Philadelphia Public school system is not the best system for children with autism. Besides the fact that, until a recent case, they were shuffling around children with autism between schools (which I will talk about in the next section), there is already violence towards children from other children. Autistic children are bullied three times more than their non-autistic siblings (O’Connor, 2012), and children who are being bullied cannot speak for themselves. And “in the Philadelphia public school system there is a lot of interpersonal violence...children with autism get bullied a lot more” (K, 3/14/13). The majority (85 percent) of students in the Philadelphia School District are students of color who are also mostly coming from low-income backgrounds. And the school district does not get much funding from the state. So not only are
the children with autism not getting the best help possible from the school, but they are bullied because they seem awkward or because they do not fit the social norms of the children. But because this is not an education thesis, I will only talk about the bullying that happens.

For children with autism, “…the risk of being bullied was greatest for high-functioning children who end up not in special education programs, but in mainstream classes, where their quirks and unusual mannerisms stand out and they are more exposed to bullies” (O’Connor, 2012). For the Philadelphia school system, there is not much help for children with autism to get put into special education classes or to have more specialized teachers, and special schools are more expensive. So it is much easier for children to get bullied in public schools versus private schools that specialize in autism. And when the children finally speak up, they are not always believed and/or the administration will not do anything about it whether or not they want to. As O’Connor writes, “at a meeting with school counselors, the [autistic] teenager finally spoke up, confessing that he was being bullied by students in the cafeteria” (O’Connor, 2012). Bullying is much more prevalent that it seems to be because the students who are bullied cannot always say anything, or understand that they are being bullied.

There is also abuse from parents or friends of the family that children with autism face that can be, and often is, worse than the bullying that they face in schools. Parents can be physically abusive, especially if they do not understand autism, because of the frustrations that come from raising an autistic child. And sexual abuse is huge within the autistic community. As I says, “kids can be sexually assaulted, and we wouldn’t know” (I, 2/19/13). It is hard to find the evidence, especially when the child cannot say anything. One therapist told me that he had a child, “who was being sexually abused for years until one day he was bleeding from his anus and I asked what happened and he didn’t have the words to indicate how this occurred” (L, 2/28/13).
It is easier to manipulate children with autism because people know that they will not be able to say anything. Toilet training is also really important in reaction to sexual abuse. It is “bigger than you think because it leads to…it has ramifications for sexual abuse, hygiene, inclusion issues, and can also be used as a big issue in independence” (H, 1/15/13). Although there are other reasons to toilet train a child, if someone needs to go in with the child, a therapist or a parent can take advantage of them in the bathroom. Parents feel a huge frustration of someone else possibly hurting their child, and the child wouldn’t be able to say anything (Osteen, 2010: 238).
Works Cited

Interviews


Articles


Books

Adams, Christina

Barnbaum, Deborah R

Foucault, Michel

Foucault, Michel

Goffman, Erving

Greenspan, Stanley I.
Hillman, Jennifer with Stephen Snyder and James A. Neubrander  
London: Routledge.

Landsman, Gail.  

Nussbaum, Martha C.  

Osteen, Mark  

Newspapers

O’Connor, Anahad  

Pilkington, Ed  

Films

YouTube  
Chapter 3 – Struggles of Low-Income Families

"In a well-ordered society where all citizens’ equal basic rights and liberties and fair opportunities are secure, the least advantaged are those belonging to the income class with the lowest expectations. To say that inequalities in income and wealth are to be arranged for the greatest benefit of the least advantaged simply means that we are to compare schemes of cooperation by seeing how well of the least advantaged are under each scheme, and then to select the scheme under which the least advantaged are better off than they are under any other scheme.” (Rawls, 2001: 59)

While autism is a struggle for everyone, low-income families cannot afford the resources that their children need. There are already givens that come out of research of low-income families with children with autism. It is true that they will not get the best care and will not be able to afford the care. However, society is not always aware of the ways in which low-income families can be manipulated by institutions. There are differences in the schools that the children can attend and the offices that parents go to for diagnosis and treatment, there are skills that lower-class families cannot provide because there is no time or money to train their kids (even though some programs are starting to give grants now), and they also get a later diagnosis.

I was fortunate to be able to go to several lectures, one of which I got permission to record. These lectures were mostly designed to give advice to parents and other caregivers about the best ways to work with their children, and others were for researchers to present their data. The one I recorded was about toilet-training, and it was very interactive, with many parents interested in talking to the lecturer and interjecting. She had a very positive impact on them, and gave advice to parents about using alarm clocks and instead of telling the child that they were going to the bathroom, “tell them that they were going on a walk” (W, 1/30/13). Then they would make it to the bathroom and the child would not have the time to feel nearly as nervous. She made many remarks that lower-income families could more easily relate to. But it was clear
that a lot of these families had many struggles in raising their children and getting the best care. One husband and wife couple was struggling, where the father was on the side of the room with his wife, and he clearly did not want to be there. He was disinterested, and moved away from his wife. He kept looking away. His wife, however, was extremely talkative, but also was easily frustrated with him. One person who saw me looking whispered that “they’re always like that.” Another parent pair that seemed to be doing well did not know that they could communicate with the occupational therapist from the school. But the lecturer and the host said that because they are paying taxes, they can take advantage of the resources that the school has. The school neglected to tell them that this was possible. This lecture was mostly for the lower-income families, and was really helpful. The lecturer, W, told me that she made the title about toilet training because “it will draw all parents, and also will provide them with a social group so that they could meet other families and have a support network” (W, 1/30/13). That way, they would also know other parents who are going through similar struggles.

Programs are also starting to be “based in an inner city [for families] with lower to moderate incomes” (N, 2/25/13). They are also in locations that are easier for parents to access. It is definitely a struggle to get lower-income families to participate though. In N’s program, “we do a lot of community events and I focus on moderate and low-income families in the West Philadelphia area, and we sprinkle around Philadelphia, so my biggest issue is the turnout” (N, 2/25/13). Transportation and late nights can often keep parents from coming because they are extremely tired and may not have the means to travel to the lecture location. Turnout is generally higher though when they are desperate to learn about the particular topic of the lecture, in this case, toilet training.
It is clear that socioeconomic background is extremely important when it comes to care that children can get. They are not treated as well in the classroom and Medicaid cannot cover certain types of treatments. “Notions of ethnicity, race, and socioeconomic status are shaped as discrete theoretical objects in some disciplines and not in others and cannot capture the variation in individual and group cultural practices” (Solomon, 2010: 248). In clinical encounters, there are differences based on status and background. In this chapter, I will explore the focus of my question, which is how lower-income families do not receive the best care.

**Autism: A Secondary Issue**

For many low-income families, autism is a secondary issue. They may not have enough money to spend on diagnosis or treatment, and health care plans do not always cover treatment. There are other things that families have to spend money on, such as rent and food, that are more important than treatment. I argue that treatment for many low-income families does not take precedence because costliness of treatment takes away from resources to take care of the basic needs for the entire family.

Many therapists and social workers recognize that parents cannot afford treatment for autism, and although they know that the way in which low-income children are raised is not good for them, there is not much they can do. As I says, “autism is the last of their concerns when they need to get food or not get shot in their neighborhood” (I, 2/19/13). B agrees that, “many times with those really challenged families, safety is a major problem. Many children with autism can struggle with maintaining safety and may not be able to communicate effectively...Obviously for families in a much higher socio-economic level, basic things will not be as much of an issue, so strategies can be related more to specifics of autism and resources that
they may have available are not as challenged” (B, 2/15/13). In Philadelphia, it is important to be able to provide a safe place for a child to live, and particularly a child with autism who can’t communicate effectively. It is more important for parents to be able to pay a little more rent to give a good home to their child and not be shot.

Related to this issue, B, a medical director of an autism center in Philadelphia, continues that, “obviously, those who struggle socio-economically, with community violence, not much hope for a great future, it is incredibly challenging. You need to make sure that basic needs are met, not just for the child, but for the family. You have to get them connected to appropriate agencies and when you’re worried about your life and safety you may not focus on those interventions. You have to help the families get as many resources as possible” (B, 2/15/13). He knows that he needs to help these families and children and wants to make their lives better, but he worries that whatever he does is not enough because coming from a low-income background is extremely detrimental to their treatment. He wants to be able to tell them that the treatments they hear about do not work and tell them that there is no cure, but he recognizes that he has to be patient. “Obviously those who struggle socio-economically, with community violence—not much hope for a great future—it is incredibly challenging. You need to make sure that basic needs are met, not just for the child but for the family. You have to get them connected to appropriate agencies and when you’re worried about your life and safety you may not focus on those interventions. You have to help the families get as many resources as possible” (B, 2/15/13). Families from lower-incomes have more issues to navigate, and he believes that it is his obligation to help these families navigate in the best way possible. He wants to help them teach their children to communicate better when they are in unsafe situations and teach the
families which battles are important to fight and which ones will not always be of benefit to their child.

Treatments also rely on parents to help and work with the children, but a lot of low-income parents can’t spend much time in their lives working with the children because they have other jobs. Therefore treatment isn’t as effective because they cannot put a full time job into their child the way that autism requires. Parents with a low-income cannot be co-therapists for their child. Families with a lower income may keep their kids in diapers for longer because they don’t even have the means or time to toilet train their child.

Then there is the problem that, “children must have access to regular pediatric care during preschool years, and easy, affordable access to a variety of specialists. Even in wealthy areas...this access is limited, and currently our developmental centers [such as CHOP] are booking appointments months into the future. For families who cannot plan that far ahead, do not have transportation, etc., this is a barrier.” (Thomas et al, 2012: 210) For children coming from low-income families, they are wait-listed at these developmental centers and do not get spots because the wealthier families who can afford the high prices move their children up on the waitlist.

Many families are also single-mother households that have even less because there is only one parent working. “In a single-parent family, raising a kid below the poverty level when your child has autism, the autism might be the least of your worries. And so working with those families as a researcher could affect intervention to meet those families where they are and with the resources that they have available” (K, 3/14/13). They do not have many resources available, and it can be hard to work with these mothers and families because researchers and clinicians
need to build up the trust and there is not much they can do when a family does not have much time, money, and energy to offer.

Furthermore, autism is not as important to some families because they simply, “have no idea what autism is and don’t know where to get help from. They have a lot of questions on how to get started and how to work with issues” (N, 2/25/13). And many cannot get started because they do not know the best way to start, because there are many conflicting ideas. They do not feel like they would be doing the right thing.

**Expensive Resources**

Throughout this paper, I will reiterate that resources are extremely expensive, so for low-income families, it is especially hard to access the best care possible. As one parent said, “[with autism], you deplete all your fundings. If you are really serious and you are looking for all the resources. [My child] hasn’t totally depleted my pocket, but there are certain things he needs. Some I can afford, some I can’t, I have to create a way to go around it. But definitely a lot of people exhaust their fundings and I’ve talked to a lot of people” (N, 2/25/13). It is not uncommon for families to go bankrupt and not be able to access certain therapists or treatments for their child. One parent, D spent pocket money on her son’s ABA treatment. Another mother, G, had to put her child into an institution out of pocket, which was hard for her emotionally but also a financial burden. As I says, people with a lower-income are “dramatically underserved” (I, 2/19/13). They do not get the best treatment, and they also have to pay for most of it with their own earnings without help from other institutions.

Of course, it is clear that there is a financial burden for everyone, and that “children with special needs may have other impacting medical needs and need to be evaluated by a
pediatrician” (A, 2/28/13). But autism is not a diagnosis that parents look forward to hearing, and institutions should be able to help care for these children. And there must always be a difference because nothing comes free in our society. As John Rawls writes, “a certain level of income and wealth is to be assured to everyone in order to express the ideal of the equal worth of the basic liberties, [but that idea] is superfluous, given the difference principle” (Rawls, 2001: 151). Low-income families do not have the access to the wealth that is essential to having equal worth in our society.

As one author writes, “intervention strategies are expensive. Many strategies require long hours of one-on-one interaction with a trained therapist or use of costly foods or drug supplements” (Sharpe, 2007: 248). Many families cannot afford these intervention strategies. Special foods and interactions with a therapist are often not covered by health insurance. He continues later that, “especially for families with relatively lower income, demands of autism diagnosis and treatment can seriously outstrip family resources. For at least low-income families, lawmakers should consider creating incentives for health insurance companies to cover some of these expenses or increase public funding for some of these costs” (Sharpe, 2007: 257). Because parents generally want to help their children, they need to prioritize autism treatment so that their resources are not completely eliminated. Many parents can also show the regression of their children with the use of home movies that they would show doctors (Silverman, 2012: 46). However, some parents from low-income families cannot do this or simply are not holding a video camera to record every milestone of their children. They have to decide if it is more important to pay for the food of their child, or pay for treatment no matter how limited it may be. These families have to constantly worry about issues of poverty.
Many parents I talked to discussed the same issue. One mother said, begrudgingly, that “a couple thousand dollars a month and insurance helps take care of needs of children with disabilities” (D, 10/25/12). Although this is more than families who have a low-income can afford, it still puts her at risk because she has to make decisions related to his treatment that may be hard and knows that she may not even be getting the best treatment all the time. G also said that, “if I’m not mistaken, in 2½ years she’s been in 9 facilities. And it’s...financially...the decisions are financially based and not a benefit to [my child]. And I’m angry about that” (G, 1/12/13). Not only is she making difficult decisions about the facilities and resources her child can access, but she also recognizes that these facilities are not always of a benefit to her child. Furthermore, because she has to worry about her finances, her daughter is often in-and-out of different facilities because they become too expensive for her. And she is not working a high paying job, has other children to raise, and as an immigrant, she cannot access health insurance.

Regardless, all families have to think about the ways in which they allocate their funds and they struggle to pay for their future and their spendings for the long-term are shortened. Sharpe adds that families are, “choosing our child’s welfare over family needs, paying for special diet foods instead of bills, putting off bills to pay for supplements” (Sharpe, 2007: 259). They limit their own luxuries and needs in order to care for the financial issues related to raising a child with autism. Parents often cannot pay bills or rent so that they can access other treatments to benefit their children.

Children with autism are an expense for families emotionally and financially which leaves parents to make hard decisions related to their child. As author Michael Berube writes, “I fear this above all: that children like James [my son with Downs syndrome] will eventually be seen as “luxuries” the nation or the planet cannot afford. I do not want to see a world in which a
human life is judged by the kind of cost-benefit analysis that weeds out those least likely to attain self-sufficiency and to provide adequate “returns” on social investments” (Berube, 1998: 52). It is frightening to believe that children with disabilities can potentially be seen as luxuries because our society often views children as providing some return on a parent’s investment. Society would be further diminishing the children and their families.

“The intensive nature of the care also creates a lot of problems in addition to the financial costs; there are opportunity costs to be able to receive that care. They have to make themselves available in a way that they might not otherwise have to. You would need to have to make that space in your life for your child to receive that care” (K, 3/14/13). Parents with children with autism have to really be available and make space in their lives to be able to get their child to treatment and to also help in the treatment process, so when they don’t have much money and need to work multiple jobs, it’s really hard for them to create the space that can be expected of higher-income families. K even adds that, “you can ask rich families to do things that you can’t ask of poor families. Often, in wealthier families where the child has been properly diagnosed, one of the parents leaves the workplace and really focuses on providing and caring for the child and I think that these children can get a greater education and these parents did the research” (K, 3/14/13). Wealthier parents can put more time and energy into their children, especially when there are two parents to help raise the child so that they can split the work. Children with autism who are low-income “can’t always access the more intensive services” (L, 2/28/13) that higher-income children can access. They do not get the same medical assistance and agencies and public services that are supposed to help them are not a reliable source when families do not have the money.
One researcher notes that the "prevalence of ASD with mild impairment increases with income, with prevalence of mild autism significantly higher in the top two income categories than in the lower two" (Thomas et al, 2012: 207). This is likely related to the fact that people with more wealth can afford treatment and diagnosis and also are more likely to be educated and understand what autism is than lower-income families who cannot afford the diagnosis and cannot afford treatment. Parents with higher income can also access better treatment for their children so that autism will become more mild with the various supplements and more highly trained therapists that they can work with. Lower-income families do not have the same access to good healthcare that higher-income families have, and wealthier families can usually receive more evaluations for their children. And unfortunately for lower-income families, they do not have the most highly trained doctors. As L said, "how well trained these people are who provide these services is a real question mark. It's pretty sketchy as far as the services that are available for [lower-income folks]" (L, 2/28/13). It is clear that higher-income families can afford the better resources and treatment, and have access to doctors and therapists that low-income families do not necessarily have.

This problem continues as the child gets older. For one, many low-income families do not diagnose their children until they are older, if they even can. And the care is not the same or it has to be more intensive because autism is harder to treat for children who are moving into an adult stage. As L says, "there is so little for kids once they turn 21...it’s a real struggle. We don’t have the resources to continue services and they don’t have access to services" (L, 2/28/13). B also talks about the fact that many agencies do not realize that long-term care is the best and most efficient way to care for the child. He says that with, "developing access, costs are high to care for this population particularly for the short-term, and it may not buy anything for 10 to 20
years and may not be convincing for agencies that if you invest early you will save all sorts of costs and difficulties down the road” (B, 2/15/13). Agencies will not willingly pay for low-income families who can barely afford to pay for a month of treatment and make it easier for them to afford treatment for the rest of their child’s life. Low-income families do not have access to good health care or to agencies that will help them in the treatment of their child.

*(Foster) Homes*

The home that the child lives in is extremely important towards their development. Many families try very hard to keep their children, but some families simply cannot afford to raise their child and put them in foster homes. At that point, the foster care parents have a hard time raising the child, but the government gives them money for being foster parents. However, that amount of money is not enough to be able to raise a child with autism. In a home with a child with autism, bankruptcy can become a reality. As one parent noted in another interview, “we have maxed out our credit card and if it gets any worse we are going to have to place our son in foster care to have all his needs met or file for bankruptcy” (Sharpe, 2007: 259) Putting a child into foster care is the last thing many parents want to do, but it is necessary for them to have a better life and for parents to make enough money to raise their other children. This does not meant that children in foster care will always receive better care, but in the mindset of their biological parents, they know that they might not always be able to give the time, money, and energy that is required of them.

Many of the families who place their children into foster care are already struggling financially, “and have other children in the household, possibly even another child with special needs. Some do not speak English and may not be able to communicate easily with their
interventionists. Some have limited education levels, do not have another adult with whom to share the responsibilities for caring for the child, or both” (NEILS, 2007: 5-2). And then, if the children are in foster care, they will have to move around frequently because foster parents only raise the children for a limited number of months, and the constant movement is detrimental to the child.

The statistics are not good when we see that, “one in seven children in EI are in foster care, a rate far higher than that in the general population” (NEILS, 2007: 5-1). Birth parents cannot afford to support the child, and must put the child into foster care as a last resort.

And this is not to say that foster care is good for the child. In foster care, “kids … have been exposed to an abusive or neglectful environment” (H, 1/15/13). Children with autism in foster homes can often be misdiagnosed because they may have difficult behaviors that stem from trauma that also doesn’t go away in a nurturing environment. But they will not have the same behaviors as children with autism. Or they can be correctly diagnosed and not be treated or make good improvements because they had awful experiences of neglect in their foster homes.

Community: Availability and Accessibility

The community that the child lives in is extremely important to their treatment. Some communities simply cannot provide the best care for children. As noted above, the community can be extremely important in treatment, especially if the parent is worrying more about the safety of their children in the community they are coming from. The community is also important because, for families with limited transportation, they need to be able to access a health clinic that can work with their child. Many families have to relocate in order to help their children.
In terms of the health clinics, many low-income communities lack availability towards good clinics or any at all. The “per capita availability of pediatricians and school-based health clinics were positively associated with the proportion of children who received a diagnosis of ASD” (Mandell et al, 2006: 1481). So for the low-income communities that have a lower rate of diagnosis, it goes to show that their experiences with clinics in their communities is related to the underdiagnoses of their children because there are few good clinics and people need public transportation to be able to get to clinics. As Solomon says, “sociodemographic characteristics as well as local health care resources and state policies contribute to disparities in the age of diagnosis, a situation that requires rethinking what being “at risk for autism” means” (Solomon, 2010: 249). The higher income, White families would rather establish the better clinics closer to their neighborhoods.

Some families, though, also do not realize that diagnosis is not always a hard step. As H says, “we want families to be able to get a diagnosis and be able to work with it, cope, and understand. People think ‘oh, we have to wait a year and a half for a diagnosis,’ but you only have to wait for a Children’s Hospital of Philadelphia (CHOP) doctor to evaluate your kid” (H, 1/15/13). But because CHOP can be hard to access for families and it is in a nicer area of University City, many families do not recognize that they can actually spend the time to get to the location for the diagnosis, even if it is expensive. Some clinics are even starting to offer grants for families to do studies. “more and more there are outside providers who provide services but for most of them it’s not compensated by anyone...there are big difference with that piece...but if you qualify for one of their studies they’ll do a full assessment for you” (E, 2/22/13). So if the child fits certain eligibilities and the parents do not have a high income, many
places will do the assessment with a diagnosis pro bono. This is important because it is not fully advertised that diagnosis can come easier for children.

There is also the issue of children not being able to be part of the community that they live in. For children with autism, this is important because it relates back to families not being able to access other families for a support network, but also keeping children in a safety net so that they cannot be harmed. One social worker explains that “the big thing is that poor families don’t get outside...there are no playgrounds, no supermarkets, no connection to other families, they don’t talk to neighbors...you might see a kid who is literally jumping off the couch and running outside because there are no playgrounds. They [the parents] sit them in a stroller until they’re old” (H, 1/15/13). Parents are not sure what the best way is to utilize their communities to help their children, and sometimes, communities are really not available to be at service for the kids. There may not be playgrounds or community centers at a more basic level, but there also may not be enough trained specialists or members of the community who can help a parent by taking in or babysitting their neurotypical children from the night. This leads to low-income children not being able to be treated because they have no real access to the outside world, cannot learn other skills, and the parents continuing to put them in diapers and in strollers because it is hard for parents to train their children or have access to people who can help them work with their children. There is not always enough community support.

Many families also have to completely leave their communities in order to get the best help. With autism, “jobs are sacrificed, opportunities for advancement are postponed or given up. Families live apart or uproot themselves altogether from their homes to get their autistic children into better treatment programs, to get them a better chance to be cured” (Cohen, 1998: 64). Families need to completely leave parts of their life in order to raise their children. They might
have a decent job in their neighborhood that they cannot access through public transportation. Or one parent has to leave with the child so that one can continue to make money while the other is living in a neighborhood that has more access. Regardless, many low-income families have to make serious decisions about whether or not leaving their community is best for their child.

**Transportation**

Another issue related to coming from a low-income community is that the families may not always have cars and need to rely on public transportation. It is not always possible to get from their communities to a specialized hospital. Not many families are available to get to a place where they can get a diagnosis or a place where they can treat their child.

Some agencies that specialize in working with low-income communities will meet them where they are. They either drive to a person's home to work with the child, or they are based in a community that has various children who are autistic and it will not take a bus or train to get to the location. However, some agencies are not easily accessible by public transportation, which makes it difficult for members far from the location to access the care. Sometimes these agencies are in harder to access locations, but are close to the families that they want to serve.

**Health Care**

Low-income families do not have the best health care. Even if they are on Medicaid, the insurance does not cover a diagnosis of autism and the treatment required. "Many states have expanded Medicaid eligibility to include children with autism, regardless of family income." (Mandell et al, 2010: 827) However, "the autism diagnosis in Medicaid claims has not been validated." (Mandell et al, 2010: 827) Just because states say they offer care does not mean that
the children with autism actually get the care. Plus this is only limited to a few states. But in Pennsylvania, as A says, “if you receive more than a certain amount, you need to meet financial eligibility to get services” (A, 2/28/13). This amount can be extremely small, and the services that they are eligible to access only provide for so much. Mandell agrees, saying that “access to care may be worse for near-poor families than for those who have public insurance” (Mandell et al, 2006: 1484). Medicaid really only does so much to help children. Ragone and Twine add that, “Women whose children’s health care was funded by Medicaid sometimes complained that medical staff looked down on them, and they worried that doctors made choices based on financial concerns rather than on the best interests of the child” (Ragone and Twine, 2000: 184). Not only did Medicaid barely give enough for treatment, but the doctors who served children with autism with Medicaid looked down upon them.

Another researcher essentially says that the services that Medicaid covers are not the best services. “While our analysis suggests that Medicaid-covered children are faring as well as or better than their privately insured counterparts, it does not conclusively indicate adequate access to care, nor does it speak to the quality of the services provided for either group of children” (Dubay: 2001, 118). Private insurance for low-income families is not sufficient for children to receive the best care, but neither is Medicaid. Both do not generally cover services for autism treatment.

Therapists and practitioners cannot ask families to do certain things based on their level of income. One example of this is that, “having many primary care physicians before diagnosis may be related to issues such as residential instability and poor access to health care that result in discontinuity of care, or parents could not recognize the importance of continuous pediatric care” (Mandell et al, 2006: 1485). Parents of children with autism have to constantly move to be able
to afford housing and also be able to afford doctors. If more therapists were willing to meet families at their level, this would not be as much of an issue so that families could continue care of their child.

It is important for children to have this constant access to care, and the care has to be good. "Having a usual source of care is considered a necessary component of continuous primary care and therefore a key indicator of access. Comparable proportions of Medicaid-covered and privately insured low-income children in our study lacked a usual source of care or relied on the emergency room" (Dubay: 2001, 114). Children from low-income communities really do not have constant care, and what is covered by Medicaid is not enough to give them good treatment. This is not fair for families who rely on their Medicaid to be able to help the child. Institutions should not limit parents of children with autism and force them to make their, "decisions to bear children [based] on financial concerns, on the state of their medical care and health insurance" (Berube, 1998: 47). Autism is also not clear during the pregnancy, so it is impossible for parents to tell that their child has a disability that will not be covered by insurance.

This political construction of health care access deeply hurts families of children with autism. As Solomon says, "some social groups appear to be more and some less equal when it comes to receiving a diagnosis of ASD; thus being at risk for autism is not only a genetic issue because of family history but also deeply embedded in structures of health care access and delivery as well as in practices of caregiver-physician interaction in clinical encounters" (Solomon, 2010: 249). Health care delivery is minimized and worsened for low-income children with autism, and the way that our society works only increases the validity of these structures to continue this trend.
Education

Education access is another issue that low-income families have to think about. It is a general rule that districts in lower-income communities are not going to necessarily be "good" in the sense that the teachers are not as well trained and their special education services will not be as helpful for the child. Many special ed teachers in low-income neighborhoods have not been as highly trained, and especially with autism, there are rules that work with other students with a disability that cannot work for children with autism.

The bigger issue with education, though, is the lack of diagnosis and the lack of treatment that the school offers. Often, "the teacher has the best intentions for the child, but financially the school can't provide what the teacher wants them to provide. And we always felt like we were going into IEP meetings not thinking that the school was on our side financially" (G, 1/12/13). Even if there are good teachers, the school district will not always have the money to help the child, or will not want to spend the money. Low-income parents would rather not risk their child not being educated at all, and do not want to make the wrong decision at detriment to the relationship with the district.

Schools also do not necessarily want to provide the services for the child. As one author write, "school districts may resist providing behavioral therapies like ABA because of the expense involved, as much as $40,000-$80,000 per child each year, and so parents have become experts of another kind, legal representatives for their children at the annual meetings required by law to settle the terms of a child's Individualized Education Program (IEP)" (Silverman, 2012: 124). Low-income families cannot necessarily serve as the legal representatives for their child because they do not always understand the process of receiving good services, and because they may not always understand parts of the law. E agrees, calling it "unfortunate" that schools
will not want to provide the necessary services for the child to have a good education. K says that this is definitely a financial issue, and parents in other districts would not have to worry about education. Much of this does relate back to the Philadelphia school district, which is not as funded and does not have the most highly trained public servants. “There are hours and hours of intensive intervention, and often insurance companies don’t pay for that, our school system doesn’t provide in the way we’d hope for, but there are not enough educators in the country to provide the care” (K, 3/14/13). The school district cannot and will not always play a role in the care of the child.

Yet, many low-income families do not realize that the school district is legally supposed to be “free and appropriate” although the services are “not optimal, and health care is designed to help people function maximally but implemented in different ways...there are a lot of cases where people are not receiving optimal treatment” (I, 2/19/13). Schools are “legally obligated to provide a fair and appropriate education to children with autism,[although] the educational programs that are provided are rarely sufficient to address the needs of school-aged children with autism and are not available to young adults with autism” (Sharpe, 2007: 248). Early intervention is supposed to be 100 percent free. It is not the best for children, and school districts are not going to provide the best care possible, especially in lower-income communities. Most schools will not even provide the TSS staffer unless parents are adamant about it, but the parents who do not know or who are too afraid will not be adamant. And it is the case that low-income families are not as aware of these issues because the school district keeps them from knowing and will not willingly share this information.

Education is extremely difficult for children coming from multicultural backgrounds. Multicultural parents are afraid of the educational system knowing that there are biases against
them and their children from the moment they walk in, and they also want their children to be accepted. When the child has autism, it already creates more issues for the child to be accepted, and they recognize that many challenges will come out of this bias. “Parents from some multicultural groups may be discriminated against by teachers and thus be uncomfortable being involved in educational decisions for their children” (Wilder et al, 2004: 107). For reasons like these, parents may not get involved in the diagnosis of their children. They do not want to face more discrimination and do not always understand what the diagnosis means and how it will affect the relationship that the child has with the school.

And with multicultural backgrounds, even in the Philadelphia and Princeton areas, “teachers may even be prejudiced against minority students with autism because the students come from a multicultural group that they dislike or misunderstand” (Wilder et al, 2004: 107). This adds to the understandable fears that parents have when it comes to their children, especially when they do not fit into the beautiful and White category. It is also true that “…ethnicity played a significant role in which students were reported as served under an autism eligibility category. Caucasian students were 1.54 times more likely to be served under an autism eligibility than all other ethnic groups were…” (Morrier, 2012: 50). Background makes a huge different in the treatment that a child will get in the school. While they are also diagnosed earlier, they are also given better treatment and will have more benefits in the public school system, if they are not in the private system. “School systems [also] did not place students from ethnically diverse backgrounds under an autism eligibility” (Morrier, 2012: 50). So being of an ethnically diverse background deeply hurts the children who need the help. They are not eligible for autism because their actions are seen simply as a part of their culture and their typical actions.
"Educators must pay careful attention to the ways in which the interface of ethnicity and assessment plays into determining a child eligible for special education" (Morrier, 2012: 60). Educators cannot base their decisions on stereotypes. Ethnicity plays a huge role in whether or not they are even diagnosed, so to treat them as if they are simply acting in a typical way is not helpful. Yet, stereotypes play a huge role in determining the treatment and diagnosis which is not suitable for ethnic groups. Society plays a huge role in determining eligibility requirements that hurt people from multicultural backgrounds. Members of the community may believe that children from different cultures act in a particular way because that is what their background determines, so requirements that may include not giving eye contact will fall under cultural reasons.

Beyond the educational factor, there are also "certain cultures where it is still not accepted to have a child with a disability and you kind of mask that a little bit more and families will not accept the label… it is seen so negatively by culture… we diagnosed a little guy and talked about what was hard for him and we did not label him because his mother wouldn’t accept it. She was from Arica where it was a sin… and the charter school bent that way" (E, 2/22/13). The school had to follow what the mother wanted because she was afraid of how she would be perceived by people of the same ethnic background to have a son who was disabled.

Late Diagnosis or Not Diagnosed At All

Late diagnosis, or children not being diagnosed at all, is extremely prevalent for low-income families. As one service worker said, "children of poorer families… don’t get diagnosed as early" (H, 1/15/13). This can be for a variety of issues. Sometimes, it is because they do not have access to physicians in their early lives. Other times, it is because the parents do not want
their children to be diagnosed and may not listen to the diagnosis because it is one more thing that they need to worry about when they already have other issues of concern, such as putting food on the table.

“There are a great number of kids out there who are not diagnosed...you’ll find research-wise...some kids are getting diagnosed years and years later” (L, 2/28/13). There are new opportunities for children that weren’t there before in terms of getting a diagnosis, but there are also many low-income families who do not want to get the diagnosis. Income generally leads to an underdiagnosis or late diagnosis because that would mean that the child needs to be treated, which is expensive, but also falls into one of the fears of the family that the child could have autism in the first place. As L states, “something along the lines of 65 to 70% of children on the spectrum through their adolescence have been diagnosed in the past year...they just couldn’t report it earlier” (L, 2/28/13). Diagnosis is only the first step to treatment, and it is already expensive.

“Children from near-poor households received the diagnosis .9 years (11 months) later than children who lived in households with incomes >100% above the poverty level” (Mandell et al, 2006: 1481). It is hard for them to get the diagnosis because of the school district, their access to a health center, or because of the expenses and fears related to the diagnosis. And once they get it, they cannot always afford the treatment.

From the readings I did and the people I interviewed, I heard various anecdotes about the ways in which people of multicultural backgrounds are diagnosed. The most prevalent answer was that they are diagnosed later, but there is also agreement that children are misdiagnosed or not diagnosed at all. Autism is not discriminatory based on race, but it does lead to changes in
the time of diagnosis that is not as prevalent in families that are White and generally of higher-income.

As one researcher wrote, “…some racial groups were overrepresented or underrepresented” (Wilder et al, 2004: 106). Although it really varies by ethnic group, it is not rare in any case to have children who are under or overdiagnosed as autistic, and most of this relates back to stereotypes that people hold of different groups. As I says, “there is an evidence-base for children who are misdiagnosed or not diagnosed at all. It’s really amazing what happened. From the research, there are dramatic rates across race and ethnicity and there is no biological base…no one has really looked into how or why, but history or racial disparities and there are cultural differences in society and what is appropriate in treatment…” (I, 2/19/13). She admits that these cultural differences create a huge variance in the ways in which we diagnose people because autism does not discriminate: it simply leads to a change in diagnosis.

Although I heard myriad responses from different professionals, it seems that underdiagnosing is more prevalent than overdiagnosing. This is where authors and researchers tend to agree. “…children with autism from racial or ethnic minority groups were less likely than white children to be diagnosed” and “the racial and ethnic difference in age of diagnosis was much less for children with autistic disorder…than for children with other spectrum disorders, for which more variability in presentation may be observed” (Mandell et al, 2010: 827). Mandell has also stated in other research that income level can play a huge role in diagnosis, so mixed with ethnic background, there is a huge reason for children to be underdiagnosed. They may not be able to afford diagnosis, but they also may be biased against.

Two authors give reasons as to why underdiagnosis is so prevalent for these children. Thomas states that “minority children are more likely to live in poorer areas, and later age at
diagnosis could result in lower prevalence ascertained at age eight” (Thomas et al, 2012: 210). In this case, the place where children live is associated with later age. Children from minority races and ethnicities generally live in poorer areas in the Philadelphia and Princeton areas, and cannot get to a place to be diagnosed, or may not know that their child can be diagnosed. The other reasoning, according to Szasz, is that, “…children who displease their “behavior raters” are classified as medically ill…justifying…their coerced treatment with drugs” (Szasz, 2009: 20). Their displease may come from the ethnic differences, and the people who are diagnosing will simply see this as eminent from their culture and the community that they come from. They are acting out because that is how they were raised.
Works Cited

Interviews


Articles

Dubay, Lisa and Genevieve M. Kenney

Hebbeler, Kathleen with Donna Spiker, Don Bailey, Anita Scarborough, Sangeeta Mallik, Rune Simeonsson, Marnie Singer, Lauren Nelson

Mandell, David with Maytali Novak, and Cynthia Zubritsky

Sharpe, Deanna and Dana Lee Baker.

Solomon, Olga

Thomas, Pauline with Walter Zahorodny, Bo Peng, Soyeon Kim, Nisha Jani, William Halperin and Michael Brimacombe.

Welterlin, Aurelie and Robert H. Larue.

Books

Bérubé, Michael
   1996 Life As We Know It: A Father, a Family, and an Exceptional Child. New York: Pantheon Books.

Cohen, Shirley

Rawls, John

Films

Horn, Elizabeth, dir.
   2007 Finding the Words. 60 min. Horn Productions.

Lectures

Chapter 4 – Culture, Immigration, and Race in Families with a Child with Autism

In doing this project, there was not much literature that I could find on the relationship between ASD and culture and race, which is why I decided to pursue it in relationship to economic factors. Low-income families in the Philadelphia area are predominantly of minority ethnicities and races, particularly from Black and Latino backgrounds. It has come to the point where more programs are being formulated around racial and ethnic backgrounds.

One person who I interviewed started their own program for lower-income families that “started off as 100% African-American and maybe now I have 3 or 4 ethnicities in the program. It has actually been great because autism has no ethnic background. It helps the kids a lot” (N, 2/25/13). Autism does not discriminate based on race and ethnicity. Yet, there are different ways in which autism should be treated based on these differences that practitioners do not always understand. “Practitioners may assume that they share with parents similar understandings of disability. Yet parents often hold other understandings of disability that are informed by deeper levels of meaning – levels and understandings with which we may feel uncomfortable, but ones that are nevertheless highly significant in parents’ lives” (Skinner et al, 1999: 492). Practitioners play a huge role in the meanings that parents construct to understand their child’s disability. So when they discriminate or make assumptions, parents will have more trouble understanding the disability, especially because of their multicultural backgrounds. They may also “interpret some behaviors symptomatically rather than culturally” (Wilder et al, 2004: 106). They hold stereotypes of different cultures that play a huge role in the way families understand autism.

More anthropological work needs to be done to sensitize us to issues affecting people of all cultures. Work “needs to be done to unpack the question of the comparative cross-cultural ethics of caregiving” (Inhorn and Wentzell, 2012: 126). The ethnocentrism of our society has
**Culture**

As a society, we tend to stigmatize people in different cultures, and many cultures also tend to stigmatize disability. In a way, that stigmatization also perpetuates the way in which we treat people of different cultures with disability in our country. However, “culture—and cultural beliefs about medical morality—cannot be represented by a single worldview or a categorical illustration of a particular mindset. In acknowledging that cultural beliefs are fluid, dynamic, and negotiable, [anthropologists argue] argue that societies and individuals are multicultural” (Sargent and Johnson, 1996: 369). Anthropologists cannot impose their own cultural beliefs on the treatment of people of other cultures.

Children with disabilities within culture are also not given the same respect and treatment that should be given. “Definitely some cultures were still not accepted...one change that I’ve seen is...when I first started working in this area the Jewish schools did not want to reach out...but then there was a huge awareness in the Jewish community...for programs to acknowledge kids with Asperger’s” (E, 2/22/13). As late as it came, communities began to accept their children with disabilities.

To be fair, though, there is not much research done on the relationship between autism and cultural difference. “Little difference exists in the expression of autistic symptomatology across cultures and ethnic backgrounds,” but research is limited for several reasons. “First, access to these populations is often limited due to geographical, cultural and language barriers...Second, recruitment is restricted by mistrust, fear and a misunderstanding of research agendas. In addition to cultural barriers, other obstacles hinder the recruitment and retention of children and families in research, such as participant’s uncertainties about risks, benefits and
protection of confidentiality and the effects of negative publicity. As a result of these limitations, small samples sizes limit the power and generalizability of analyses” (Welterlin, 2007: 751). Families of different cultural backgrounds are afraid to participate in research related to their child’s autism because they fear that there might be consequences or might harm them or their children, which also hinders them in the care that they can receive. It is also harder because of the limitations that the quote enumerates.

“Studies of cultural contributions to treatment decisions among children with other conditions...have found that...those who are less acculturated have lower adherence to physician-prescribed treatments, giving some evidence of the critical relationship between culture and treatment decisions” (Mandell: 2005, 111). It is extremely important that therapists work with families of different cultures to figure out the best treatment plan for children. Therapists are extremely important in the ways that families choose to pursue treatment, so if there is no trust because of culture or because the therapist will not work with the members of a specific culture, families will be less likely to pursue treatment.

Health clinics are particularly important in the construction of health culture, as many health clinics are “limited in their capacity to provide appropriate cross-cultural services” (Welterlin, 2007: 749). Clinics tend to follow the general rule that the mainstream culture is the way that all patients will look towards health care, and as Harry says, “in practice, the tendency has been to assume that mainstream values should provide the cultural reference point for goals and services. In addition, practitioners tend to treat cultural values and norms as if they represented the characteristics of entire groups or subgroups, and they find it difficult to address the tremendous variation that exists at the individual level” (Harry et al, 1999: 125). In thinking this way, clinics limit themselves in being able to access all communities that will need help.
Engagement is a huge issue with culture and treatment. Researchers and therapists have a hard time trying to get access to these populations in ways that will also not take advantage of them because they are vulnerable populations. I says, “we constantly struggle to engage those [immigrant and multicultural] populations effectively in research projects and surveys...they are very disenfranchised in the system for cultural and structural reasons...they are given a form in a language they don’t speak and they don’t know how to engage the systems...so how do we get those communities involved? We need to start to think critically about how we serve underserved populations” (I, 2/19/13).

Culture poses barriers to families who are trying to access the best care. It is hard to involve parents of various cultures in research, it is hard to get them materials, and they are afraid of the system so much that they would rather not play a role in research because they think it could put them, their child, and their family at risk. As B recognizes as well, multicultural parents are not always coming from the best education. “People who have more education might be able to read more things and understand more things and many families these days read everything and will ask sophisticated questions. And there are cultural issues that also play a role...we have to be careful in making assumptions and recommendations based on someone’s culture...so sometimes there is a balancing act to get across what you think is important and getting across what family needs are” (B, 2/15/13). It is hard for doctors and practitioners not to make assumptions about multicultural parents with the stereotypes that we hold in society, and also because certain issues seem so clear to other members of our society. For the purpose of this paper, I define multicultural as the representation of various cultures within a society. Multicultural parents even have different ways of parenting that may raise problems when it comes to getting access for their children and receiving a diagnosis. As K says, “there are
multicultural issues and how they think about parenting in general and how they think of autism, how do they think of it as a medical condition, there are all important issues that the clinician must be sensitive to” (K, 3/14/13). It is hard to be sensitive to the issues of multicultural parents, but it is necessary in order to work with them to get care for their children.

Education also plays a huge role in culture and autism. “Multiculturalism must be a focus of efforts to educate students with disabilities. Because of the possibility of misclassification and the potential for multicultural students with autism to interact with individuals in the dominant culture, teachers and other professionals should attend to multicultural issues when identifying and teaching students with autism” (Wilder et al, 2004: 106). Students may be biased against, and teachers may not necessarily know how to interact well with their students who are autistic of multicultural backgrounds.

Culture also plays a huge role in the ways in which families will fight for the best care. As A says, “it might be that it ties back into what family culture or the dynamic is like...they don’t fight for themselves in the same way because it is culturally not accepted” (A, 2/18/13). So even if they are trying to get the best care for their children, they may not access the best care because culturally they learn not to fight these battles. Plus, in this society, they are so disenfranchised that they may feel that trying to get better care is a lost cause.

Ethnicity

I am using ethnicity as a subset of culture, which will be the identification that a group has based on a common heritage whereas culture is a learned set of beliefs.

Ethnicity plays a huge role in the ways in which families understand autism, as part of an umbrella of autism. People of different ethnic backgrounds practice their culture in different
ways and also are more likely to be lower-income. As Mandell notes, “differences by ethnicity may be associated with poverty” (Mandell et al, 2005: 1481). Ethnicity is also related to various other issues, including low-income, and Mandell notes that income level “had a stronger association with age of diagnosis...It also may be that caregivers with greater resources, especially among the ethnic minority families, were more likely to respond to this survey, thus biasing the relationship between ethnicity and age of diagnosis” (Mandell et al, 2005: 1483).

Ethnic families are more likely to come from low-income backgrounds, but he also recognizes that the ethnic families that responded to his survey about treatment of autism were generally coming from more resources and a higher income. Their income made a huge difference in the way they could treat their children.

Ethnicity and income are so closely intertwined that ethnicity plays a huge role in the ways in which autism is diagnosed and treated. More research is being done about the disparities in care of children with autism, but many of the service workers I talked to said that stereotypes and cultural aspects affect how autism is treated. Plus, “parents in many ethnic groups may experience difficulties due to language barriers, lack of familiarity with cultural expectations for appropriate help-seeking behavior, or professionals who do not understand or appreciate fully the implications of cultural and ethnic variation in values, goals, and behavior” (Bailey et al, 1999: 368). They try, but they do not know what the best action is that they can take to help their child.

White families have a much easier time getting a diagnosis and treatment. “Studies suggest that Anglo families both anticipate and experience fewer barriers to obtaining health services than families of other ethnic groups” (Bailey et al, 1999: 368). It is clear that ethnicity affects the ways in which families may have obstacles to get treatment for their child.
Religion

For people of different religions, autism can be seen as a punishment or a blessing from God. In most cases, where the diagnosis is female-oriented, autism is seen to make a better mother, or the woman was already a good mother and God knew and wanted the child to be in a good home. Therefore He put the child with the mother who was good and would create a good home. In few cases, autism is seen as a punishment. There is a connection with autism to religion and culture (Skinner et al, 1999: 486). Religion provides mothers with a way to see themselves as worthy of God, and God made them have a child with a disability. If they are not already good mothers, they are worthy of being a good mother and change for their child. Being a good mother is extremely religious.

Skinner interviewed 150 mothers of children with disabilities, and for most of the mothers she interviewed, “it is likely that their image of themselves as the devoted, sacrificing, suffering mother as well as their emotional attachment to that identity were shaped in part by Catholicism as interpreted and practiced by many Latinos, where those who suffer and sacrifice are seen as morally virtuous” (Skinner et al, 1999: 487). Much like God, they sacrifice for their children to provide for them the best life possible.

Race

Parents often care about the well-being of their child, and this is true in different races although care is practiced differently. As N says, “you don’t look at racial barriers or anything. Everyone is looking for the same thing, everyone is fighting for the same cause, everyone wants help” (N, 2/25/13). Everyone wants the best for their children, and everyone is looking for help wherever they may find the help.
However, racial stereotypes may change the way in which children are diagnosed for autism. Especially for low-income families, there is more of an inclination for clinicians to fit the families into the stereotypes because they cannot afford to change the bias. Therefore, “Black, Hispanic, and “other” race/ethnicity children had lower odds of having a documented ASD classification than did White children” (Mandell et al, 2009: 495). They fit in autism with the biases they already hold of minority races.

However, higher-income White families generally have less issues with getting a proper diagnosis. As one researcher said, “it is different across communities. Different needs should be considered and addressed...We see over and over in autism research that Caucasian, upper-class families are participating and there are barriers for underrepresented families to participate” (I, 2/19/13). White families can participate more in the diagnosis of their children and will get a better, faster diagnosis and will be able to start treating their children much earlier than minority races will be able to treat their children.

White families are more likely in general to have a higher income, especially in the Philadelphia and Princeton areas. So when it comes to early intervention, “The strongest predictors of health status at 36 months were health status at EI entry, followed by race/ethnicity with white children being healthier. Because poverty, race, and maternal education along with several other factors have been found to be predictors of health status at entry, the emergence of race/ethnicity as a predictor at 36 months...indicates that health differences between white children and minority children in EI became even larger between entry and 36 months” (NEILS, 2007: 3-15). White families can give the time to work with their children, especially when they are coming from higher income. Race becomes a huge dividing factor within children who are getting treatment for autism.
Latinos

Many Latino families are coming from immigrant backgrounds, and they feel mistrust and fear of the institutions and clinicians in these institutions. But like all other families, they want to be able to help their children as much as possible. There are definitely language barriers and religious barriers that keep them from giving the best treatment possible to their children. Although African-Americans already have a low chance of getting diagnosed, “Latinos have a lower probability of accessing services than African Americans” (Wilder et al, 2004: 106). This could relate to the fact that they do have other barriers that African-Americans do not necessarily have. Plus, because of their religion, they would not necessarily want to get diagnosed because of the stigma that will come from their society with diagnosis. Although parents are extremely accepting of their children, they recognize that their family will not be supportive, and they also know that marriage prospects will also decrease which is extremely important in the Catholic faith.

But Catholicism is also extremely important in the ways in which religion can cure disease. As Bailey notes, “researchers of Latino cultures have confirmed the importance of religious beliefs, often associated with Catholicism...for curing disease or disability or ameliorating their symptoms” (Bailey et al, 1999: 369). Catholicism holds a promise for Latino families that their children can be cured. Related to this, “Latino children recently diagnosed with autism were six times more likely than children of other ethnicities to use nontraditional treatment strategies” (Mandell: 2005, 111). Latino families try other ways based on religion to treat their children. This can be the power of prayer, or it can relate to the family networks. However, there is not much research done related to the types of treatment strategies that
families use, but they fear and respect the diagnosis and try to help their children make treatment easier.

Clinicians also have to work with building trust in the Latino communities. As one researcher notes, “There are definitely differences in the way we interact. For Latino or of other racial or ethnic minorities you should wear jeans and sneakers, or they may think you’re from the government or that they’re in trouble and they won’t interact with you” (L, 2/19/13). Especially if they are immigrants, they will not willingly interact with people wearing more formal clothes because of the fear that they did something wrong. They already have other fears that are not just related to their child’s autism.

Hispanic children not being served as well as children of other racial groups (Dyches et al, 2004: 220). They are probably the most underserved of the racial communities, and we need to find ways to make it easier for them to access resources. They are mostly from lower-income families and have less understanding of what the diagnosis means.

African-Americans

Much like the Latino population, African-Americans also experience discrimination in the treatment of their autistic children. They are diagnosed much older than White children (Mandell et al, 2010: 822), which ends up averaging to about a year and a half older than the White children. Many African-American families are also on Medicaid, and the benefits of Medicaid do not always cover the treatment that children with autism will need. These children are “diagnosed on average at 7.9 years of age, 18 months later than are Caucasian children on Medicaid…” (Solomon, 2010: 249). Generally, it is better to diagnose children as early as possible, and after five years of age, it is very hard to treat children who have autism.
They also receive the diagnosis much later because they need to go in for more treatments. As Mandell notes, “African-American children required three times the number of visits over a period three times as long as European-American children before receiving an autism diagnosis” (Mandell: 2005, 112). They also do not get the same care the White children may get. They are treated as if this is part of their daily life and not a clinical diagnosis. Clinicians may base their diagnosis on their stereotypes of African-Americans. They may have “different expectations about treatment and service needs by ethnicity and may therefore not screen for ASD in African-American families as quickly as they would among white families.” (Mandell: 2005, 112)

Low-income African-Americans do not know how to handle the discrimination. They do not always know what opportunities are available to them, and not as many people will want to work with or specialize in autism, especially for different races. They may also not want to get a diagnosis because of the “fear of stigma” (Dyches et al, 2004: 220) that is extremely prevalent in African-American families who fear that physicians will overlook their child’s struggles. But, as N says about his program, he worked with a single African-American mother with low income who has an autistic child and who had to “have determination” (N, 2/25/13) because otherwise, she would continue to stay pessimistic about the care of her child.

**Immigrants**

Although the purpose of my research is to explore the struggles of raising children with autism from low-income communities, there is a significant amount of research that relates to immigrant families who are also coming from low-income families and have other barriers with regards to finding resources. Many families come to the United States specifically because of the
better options for treatment that are here, whether they are from the United Kingdom or Guatemala. Unfortunately, immigrants are limited in many ways in getting the best healthcare for their children.

The language barrier is probably the biggest obstacle for them to access resources. It stops them from knowing what is available, finding the professions who speak their language, and then they cannot understand what is available or even understand what autism is. And because they are also lower-income, they don’t necessarily have the funding to access treatment for their children.

Where to Start?

Before coming to this country, many immigrants had never heard of autism before. When they put their child into the school system, usually a child who is older than 3 years old, which makes early intervention much harder, they hear the words that their child has autism and have no idea what that means, much less how that will affect the relationship that they will have with their child and the funds that will going into helping their child. They also do not understand what it means to work with their children, and may already have a limited knowledge from a limited education. There are things that are more important to immigrant families that aren’t necessarily about focusing so much time/energy to teaching kids how to use the bathroom.

Regardless, “there are some immigrant families who never had the opportunity for educational resources and they don’t even know what to ask, so it can be a real issue and a lot of institutions rely on families...centers like ours know what rights they have and what services they should be requesting...” (B, 2/15/13). Immigrants are constantly trying to do the best they can for their child, and especially when so many had never heard of autism before, it can be a
real challenge to work with them. They also need be respectful of the fact that, “families who immigrate to the USA may have specific views of what constitutes a disability, which may be largely based on their unique social and cultural background” (Welterlin, 2007: 750). Many families may not see that their child with autism actually has a disorder that can be treated and worked on.

Even so, it is true that there is a large proportion of misdiagnosis and underdiagnosis that comes from immigrant families. As H says in our interview, “the immigrant and poorer families get diagnosed early” (H, 1/15/13) and M agrees that “A large population of children who get misdiagnoses are children from immigrant families” (M, 1/15/13), but these diagnoses are usually related to the lack of understanding that therapists have related to the issues of immigrants and also the stereotypes discussed in the earlier chapter about multiculturalism.

“In the full transcription of the 150 interviews we examined, mothers spoke of a range of experiences and events that came from having a child with a disability. Some of them recounted the initial denial, depression, and shock they went through, and the extra effort that caring for their child demanded of them and their families. Some spoke of the struggle of getting services and stress due to limited resources. A few single mothers attributed the father’s leaving to the child’s disability” (Skinner et al, 1999: 486). Mothers do not know what causes the disability. They are afraid, and they go through a wide range of emotions related to the diagnosis because of the work that was demanded through having a child with autism.

So, “despite limited research on the prevalence of ASD in recent immigrant families, it is clear that these families exist and are in need of health care services. Moreover, rising rates of immigration into the USA has resulted in more referrals to health care clinics from heterogeneous groups. Many of the immigrant families referred have different values and beliefs
to native born Americans and lack knowledge about how to navigate health care services.” (Welterlin, 2007: 748). This is why more and more programs are beginning to work more with immigrant families to better explain the results of the diagnosis and explain what autism is in a way that the families can understand. H says that her organization tends “to specialize more in working with poor intercity families with a predominant population of immigrant families. Most affluent families have better or easier access to other services…” (H, 1/15/2013). The Philadelphia area has many children, and thousands of children who are diagnosed with autism, many of those children coming from immigrant backgrounds. These organizations are needed to improve the quality of life of the people who are coming to this country to find a better life for their children.

H also notes that immigrant families tend to see their children as part of the economic unit, and because immigrant families cannot always be there to raise the children, they also want children to find some smaller jobs. Zelizer writes that, “studies of immigrant families, in particular, demonstrate that the child was an unquestioned member of the family economic unit” (Zelizer, 1985: 68). Immigrant families tend to see their children with autism as playing a role in the economic unit and want them to become more financially independent.

Health Insurance and Financial Issues

For many immigrants who wanted to find help for their children, they believed that the United States would have more resources in general available to the children. This is true; the US is much more equipped than other countries to make the diagnosis and also be more understanding of issues. However, that does not mean that the resources will be available to immigrants.
Families relocate from other countries for their children. As one parent said, “the reason we came out to this country was to help. The resources here are more helpful. In the UK, where she was diagnosed at 5...we came here at 6... She went to a special school there and that was it. When we came here the school was much more aware about how to educate a child with autism” (G, 1/12/13). The United States is known to have better clinics and hospitals to help the children, but what G found was that, although the resources were better, in many ways the resources made her daughter worse. And even when the families come, we need to help the families access the resources. “These services don’t exist in other countries, and here they exist and it’s a matter of finding them and helping them to access” (L, 2/28/13). Plus, financially, they are not always able to get the services. So once they find the resources, access is nearly impossible.

Therefore, therapists have to start working with the families to figure out what they have, what their strengths are, and what resources they can definitely access. “Financial resources and immigration status further impede health care use. In most areas of the USA income and insurance coverage determine the ability to obtain health care services. Many recent immigrants have moved to the USA in search of economic stability.” (Welterlin, 2007: 755) They often work low-paying jobs and don’t receive benefits, and may also not know how to access the free and appropriate education available under the Individuals with Disabilities Education Act. “Some families, however, may not be aware of these services and may not enroll their disabled child in the public education system” (Welterlin, 2007: 755). It is extremely important to form the treatment plans alongside the issues that immigrant families have to handle.

One of the personal anecdotes that a therapist gave me was, “I had a family that we just started working with and they brought in...a child who was 4 or 5 years old, they spoke limited
English, the father didn’t make a lot of income...they’re basically taking it upon themselves to keep the children from the outside world and now [the world is] opening up and giving them support, early intervention, transitioning from another school, easing access...we want to help them access what is out there” (L, 2/28/13). This therapist, who also has a sliding scale and insurance policies that other therapists do not always have, is taking it upon himself to work with the family and make sure that the child will be able to access health care even with their limits. He works hard to find translators so that he can communicate more effectively, and creates plans with all of his parents so that they can feel more comfortable. He gives honest answers and also puts his office into an accessible location for all parents with hours that work for them.

Hispanic families have another range of issues that other immigrants do not necessarily have. Chipres lists out all of the problems that Hispanic families may have, which includes that they could not take the child to regular doctor checkups for the first 3 years of life, they do not always understand results, they may have never heard of autism prior to diagnosis, and they do not really know other families or support groups for parents (Chipres, 2007: 45). The rate of autism in Hispanics is definitely related to socioeconomic factors; they cannot communicate, therefore they do not get diagnosed, and there is also a bias in the health care providers who do not understand them and who the Hispanic families do not understand.

However, even though autism is prevalent in Hispanic children, they are extremely underrepresented in research related to autism. This could indicate “systemic problems with identifying this group of children and youth within the autism spectrum, which is especially troubling considering this is the fastest growing population in the United States” (Morrier, 2012: 60). Hispanic children were extremely underrepresented in both of the areas in which I did my research. Again, this could be related to the income of Hispanic families, where Hispanic
children as compared to non-Hispanic white children are “3 times more likely to live in households that fall below the poverty line, twice as likely to lack a regular source of medical care, and 1.3 times as likely to experience difficulty accessing care” (Palmer et al, 2010: 270). Hispanic children are completely underserved, and do not have the same access to health insurance that children deserve.

**Language Barrier**

The language barrier is one of the most important issues that faces immigrant families in the diagnosis of their child, and also is an obstacle for teachers and therapists who try to work with them. Even in blogs, articles, and biographies, most of the families are from White, higher-income families who are also educated. And immigrant families cannot read or write necessarily, and will not always have the resources that this literature says is the best to work. They cannot understand correspondence from schools, and there are not many bilingual specialists to work with them either from schools.

Schools have to start providing specialists in order to work with the children and diagnose and treat them. Embarrassingly enough, sometimes the language is incorrect or even when specialists are trying to be helpful, they can end up being insulting. In one example that a therapist gave me, there was a Mandarin translator, but the family “didn’t speak Mandarin…they spoke Cantonese, and we didn’t want to be insulting them” (L, 2/28/13). Specialists are still trying to work out the kinks in these sessions, but they recognize that they “have to explain a little more just to get them to understand the process and where you’re going…we have to try to have interpreters at meetings so they can hear the process in their language” (A, 2/28/13). They
are really trying to help the immigrants in the Philadelphia and Princeton areas, especially since there are so many.

"Assessment practices for identifying students with autism should include both a native language and an English language assessment to determine which language should be used to communicate with the student" (Wilder et al, 2004: 108). Not all schools can provide the assessment in the native language, and therefore communication with the child can be extremely limited. Communication is already extremely limited with children with autism, so if they do not understand English, providers can do less to help the children.

Lastly, "a limited understanding of cultural differences may further alienate immigrant families and may cause low treatment adherence if interventions are inconsistent with a family’s cultural beliefs" (Welterlin, 2007: 749). Immigrant families are already alienated by their limited proficiency of English, and when the treatment does not follow with their own set of values, they cannot explain their sensitivity and must also have to accept what they disagree with.

**Education**

Educating immigrant children with autism is particularly hard. Many schools cannot communicate with the parents or the children, and families cannot always understand the IEP. Parents will also not attend meetings regarding the child’s education and/or therapy (Chipres, 2007: 51) because they have to work multiple jobs, do not have a way to get to the school, or know that they will not understand and will not have an interpreter. Language barriers are probably the most prevalent obstacles. "The language barrier these Hispanic families encountered created different challenges in learning about the disorder and participating in their child’s education" (Chipres, 2007: 51). Plus, most immigrant parents had never heard of autism.
But their language stopped them from even understanding autism and helping their child be treated for the disorder.

Schools are also not helpful for parents who do not understand the diagnosis. Especially for Latino immigrants, “...only 29% of school systems used the child’s native language of Spanish for the assessment as required by federal law” (Morrier, 2012: 50). Schools are supposed to provide the best education, which means that the assessment also needed to be in Spanish, but because they could take advantage of the parents immigrant, low-income background, they do not take the extra step to help the children and parents. Schools also “often used inadequate communication methods when interacting with Latino families” (Bailey et al, 1999: 369). They do not meet parents at their level in talking about the diagnosis and in talking about further steps that the district can and will take to help the children.

Children of Latino immigrants are also underclassified in this research because they are always underdiagnosed. As Morrier writes, “children classified as Hispanic are consistently underrepresented in special education under an autism eligibility...” (Morrier, 2012: 51). Because of the discrimination that they face even in the world of disability, parents cannot get the best help for their child that comes from diagnosis. Plus, “for each 10% increase in Hispanic children in school districts, there was a corresponding 11% decrease in students diagnosed with autism. Notably, for each 10% increase in Hispanic schoolchildren, there was an 8% increase in children with intellectual disabilities and a 2% increase in students with learning disabilities” (Palmer et al, 2010: 270). While Hispanic children were still diagnosed as having a mental disability, they were not given a diagnosis of autism. It is entirely possible that white students simply had more resources to be diagnosed since most Hispanic children were living in lower-income means and didn’t have a way to get to a doctor or afford the necessary treatment.
Fear and (Mis)trust

With immigrant families, there is much fear and mistrust of the system and of corresponding institutions. "There is always that little fear of authority...immigrants...a lot of them are afraid or coming from countries where you don't question authority" (A, 2/28/13). They are constantly in fear that they might be caught or be doing something wrong, and they also recognize that it is better for their children to be in the United States to get better care.

Many agencies also try to learn about families so that they can learn how to best help them. But the "methods by which agencies recruit families for study should be reported in detail, as some families from minority cultures may not readily participate because of language barriers, mistrust, fear, or misunderstanding" (Dyches et al, 2004: 215). As much as people may try to help immigrant families and do research to better the lives of their children, they do not always understand what the research entails, and do not know what sort of forms they are signing to help their kids.

Also, they do not want to question authority and what might be best for the child, because they do not know the other options and listen to what people tell them to decide what is best. As Bailey writes, "if other services were not mentioned, these parents seemed to assume that no other service existed or was necessary" (Bailey et al, 1999: 376). Immigrants do not feel empowered enough to question what they are told. They fear the system and mistrust what they are told, but there is nothing else they can do except for listen.

The Constant Battle
For immigrants, and all people, autism is a constant battle. Mothers (and fathers, if they are around), always have to fight for services for the children, and learn how to fight those battles. They have various jobs and do not have time to work with their children forty hours per week. They cannot support their children’s programs. They don’t really know other families or support groups for parents. Many cannot take their child to regular doctor checkups for the first three years of their lives.

When they first come to the United States, many immigrants believe that disability is more normal and that in the United States, they would also be more likely to find treatment for disability. “Immigrant families who have more positive views of individuals with ‘disabilities’ may be disillusioned when they encounter negative appraisals of their child’s disability upon arrival in the USA” (Welterlin, 2007: 750). They thought that their child would be more accepted in this new society that they thought would also provide better treatment, but they were wrong. And a lot of this is also because they are immigrants, people of color, and low-income.

Immigrants also have a lot of trouble with acceptance because of their location, which is another constant battle. “With immigrant families it depends on the circumstances...if you’re in the inner-city and also have a language barrier that’s very difficult” (E, 2/22/13). They cannot move around as well, and they cannot communicate where they want to be so that they can move around. Location is extremely important as to where programs are placed, and social workers I talked to have “visited our [other location] and had just gotten into a conversation with the secretary about autism and talked about how children raised by a mother who doesn’t speak English and can’t take the child outside so the child has really had very minimal exposure, no playground, no other kids to play with...so when they’re being evaluated, they don’t socialize or look people in the eye...is it autism or their environment?” (M, 1/15/13). The child is stopped
from interacting with other people, and the mother is afraid to let the children have too much freedom. Immigrant families worry more about their child with autism because they would not be able to communicate, whether it is because they lack communication abilities or because they do not know English. And when they are in bad neighborhoods, they also have to be extremely protective.

Therapists are starting to “follow-through for obtaining special ed services” (H, 1/15/2013). Therapists are trying to work with cultural values within immigrant families to accept that their child has autism and also help them obtain the best resources possible.
Works Cited

Interviews


Articles

Bailey, Donald with Debra Skinner, Patricia Rodriguez, Dianne Gut, and Vivian Correa.
1999 Awareness, Use, and Satisfaction with Services for Latino Parents of Young Children
with Disabilities. Exceptional Children 65(3): 367-381.

Chipres, Lourdes.
2007 Experiences of Immigrant Parents of Children with Autism. MS dissertation, Chicago,
IL, Saint Xavier University.

Dyches, Tina Taylor, with Lynn K. Wilder, Richard R. Sudweeks, Festus E. Obiakor, and Bob
Algozzine
34(2): 211-222.

Harry, Beth with Robert Rueda and Maya Kalyanpur.
1999 Cultural Reciprocity in Sociocultural Perspective: Adapting the Normalization Principle

Hebbeler, Kathleen with Donna Spiker, Don Bailey, Anita Scarborough, Sangeeta Mallik, Rune
Simeonsso, Marnie Singer, Lauren Nelson
2007 Early Intervention for Infants and Toddlers with Disabilities and their Families:
Participants, Services, and Outcomes. Final Report of the National Early Intervention
Longitudinal Study (NEILS).

Mandell, David, with Maytali Novak and Cynthia Zubritsky
2005 Factors Associated With Age of Diagnosis Among Children With Autism Spectrum

Mandell, David with Lisa D. Wiggins, Laura Arnstein Carpenter, Julie Daniels, Carolyn
DiGuiseppi, Maureen S. Durkin, Ellen Giarelli, Michael J. Morrier, Joyce S. Nicholas, Jennifer
A. Pinto-Martin, Paul T. Shattuck, Kathleen C. Thomas, Marshaly Yarrowin-Allsopp, and Russell S. Kirby

Mandell, David with Knashawn Morales, Ming Xie, Lindsay Lawer, Aubyn Stahmer, and Steven Marcus

Morrier, Michael and Kristen Hess.

Palmer, Raymond with Tatiana Walker, David Mandell, Bryan Bayles, and Claudia Miller.

Skinner, Debra with Donald Bailey, Vivian Correa, and Patricia Rodriguez.

Solomon, Olga

Thomas, Pauline with Walter Zahorodny, Bo Peng, Soyeon Kim, Nisha Jani, William Halperin and Michael Brimacombe.


Wilder, Lynn K. with Tina Taylor Dyches, Festus E. Obiakor, and Bob Algozine

Books

Inhorn, Marcia and Emily Wentzell, eds.

Szasz, Thomas
Conclusion

“The moral dimensions of medical care are viewed by anthropologists as inextricably bound to culture. Ethical components of medical beliefs and practices are culturally constituted, embedded in religious and political ideologies that influence individuals and communities at particular biographical and historical moments.”

~ Carolyn Sargent and Thomas Johnson, 1996: 357

In this thesis, I attempted to bring issues of autism to light with regards to parents who are coming from the bottom of the socioeconomic hierarchy in raising their child with autism. In this work, I wanted to give an honest look into the lives of these families, and how therapists, social workers, administrators, and myriad other groups and people are trying to help the children thrive. Children of families in marginalized communities are not given the best treatment for their autism, and their socioeconomic background impacts the care that they can receive. Their background also and leads to disparities in diagnosis, treatment and support across various axes of inequality.

Of course, there are some problems and some people and institutions that are not working as hard to help the children and are mostly working to help themselves, but I believe in the goodness and honesty of the people who I talked to in trying to make the lives of these children easier and make resources more available.

This research shows the imminent struggles in the lives of families who are trying to get help for their children. There are many problems in our health care system that limits people living at the bottom of the socioeconomic hierarchy, and this becomes hard for autism as with all disabilities. Autism treatment is rarely covered by Medicaid, and parents also see treatment as a secondary issue when the welfare of their children is more important. They have to make difficult decisions about the lifestyle that they want their children to live, and also recognize that there are so few ways for them to access good care.
Recovery

There are many views about recovery of autism. Children who undergo large bouts of treatment can grow out of their diagnosis of autism (Carey, 2013). However, it seems like the consensus is that socially, children will not grow out of their autistic traits, and this is not equivalent to a full recovery. They will continue to have some awkward traits or have tics that they need to think about so that they do not perform these traits. There is essentially agreement that children will be able to “recover” through hours of treatment, but there is “no pill for autism and parents always ask for the pill that makes them better...They want their child to recover from autism” (L, 2/28/13). Therapists struggle in this knowledge because there is no easy way to tell parents that it will take a long time to help their child, if the children can grow out of autistic traits at all. And especially for low-income families who do not have the resources, this is a disheartening piece of knowledge. Recovery also generally depends on where the children fall on the spectrum, where generally higher-functioning children are more likely to recover.

Another therapist has said that, “another challenge is helping families sort through these challenges and making good decisions. People desperately want to believe that there is that cure, that miracle, but treatment is so intense that it is difficult not to consider those things...” (B, 2/15/13). The intensity and invasiveness of treatment almost makes it impossible for low-income families to play a huge part in their child’s life. Parents need the support to learn how to best help their child, and therapists need to learn how to be there to support the parents.

Another administrator has said that recovery is not possible because, “recover to me is like your arm heals after it’s broken...a child with autism, even if they learn, they still have to go through the mental coping and that is where stuff gets better but never really goes away...” (A,
In this mindset, recovery is possible in the sense that they will no longer be diagnosed with autism and they will learn how to get over their tics, but they can still be depressed and have to go through general mental coping. There are other social cues that they will also never understand and it will take a lot for them to be able to connect things that are easier for typical children to understand. One therapist agrees saying, "...I don't think that autism itself is something to recover from; it is a part of who you are and if we’re working in ways to increase functional abilities, we want to find ways to make them happy and be an active member of society" (L, 2/28/13). For him, the purpose is not to treat the autism and get over it because it is a part of who they are. It is a matter of setting new goals for the children and teaching them how to have an easier time in society and adapting to the social norm. For some parents this is difficult because they, “have hopes and aspirations that their child will do well in the world, have friends, enjoy school, adopt a trade or career, and marry and have children of their own. For parents of children with autism, this dream is often replaced with fears and nightmares.” (Hillman et al, 2007: 44). Therapists are working with parents to change this perception and make them stronger.

It is possible to be positive, even knowing that recovery is not always possible, and if it is, it is a long road. In the research perspective, “there is evidence that there are very small portions of kids with autism who, when they have early or intensive intervention, that they may no longer qualify for diagnosis” (I, 2/19/13). Although it will take a lot from low-income families, if there is enough support, their child may be able to grow out of the diagnosis. Another administrator has said about recovery, “never say never. We won’t stop trying. We’ll still continue to keep trying to teach them. It’s possible...can everybody learn everything? No. There are limitations” (J, 1/18/13). She believes that we should never give up on people with autism.
because she believes they can all become functional members of our society. Social workers H and M agree that people don’t recover, but they can adapt enough so that autism doesn’t interfere with their everyday life.

With more diagnoses of autism, and one in 88 people in our society diagnosed as autistic, people lose hope that their child can get better. But one parent, and administrator, has taken a healthy view. He shares, “I have started to think about what I’m grateful for and what the definition of success or overcome [are]...it has changed me a lot...and now a lot of my families are newly diagnosed, and I tell them my story...” (N, 2/25/13). He has seen huge improvements in his son, and wants all families to think positively that their children can get better if they are determined. He also comes from a lower-income background, and wants the families he works with to feel the same hope that he feels. As the brother-in-law of author Christina Adams said, “I don’t think recovery is the right word. I would use reclamation.” (Adams, 2005: 236). We must work to help children reclaim themselves, and create stability in their lives with the institutions that impact them.

*Are we Serving Kids Well?*

We also have to wonder if we are serving our children with autism well. The case that I was referring to in the last section was iterated to me by a therapist, E, who told me that the Philadelphia school system was shuffling around children with autism. And because of the way that the grades are broken down, they were able to do it. This was not good for the children because children with autism do not adapt to change well. But parents sued, and now the school system is not allowed to shuffle the students, even though it can still happen because the school district can easily get around this law.
In terms of the public school system, special education teachers are not always helpful towards the child. They do not always know how to work with children with autism, and especially in systems that cannot pay teachers well, there is a lack of motivation to do well. “Just because someone is a special ed teacher doesn’t mean they have the skills [to work with children with autism]. You can’t use the same techniques for children with autism...there also aren’t enough skilled clinicians” (H, 1/15/13). Not enough people are trained to help these children. They may also not take their jobs seriously. One administrator “had 2 caseworkers reassigned from a case because they weren’t doing their job. With those kinds of jobs or responsibilities, there is a lot of freedom...it is so easy to get distracted and not pay attention to what your child’s needs are” (N, 2/25/13). He does not want the children to be left behind, and does not want someone to feel as if they can ignore the child. In many ways, we are trying to serve our children well, but cannot because there are not enough people who can work with the autistic children.

While we are lucky in this area to even have schools for autistic children around, there are not many people who can afford them. And as a general rule, there are not many schools for autistic children, and of the few that exist, even fewer are of good quality. However, in the Princeton area, there is one school that, although it is expensive and mostly White children, is truly beneficial for the children who go there. The program administrator, J, has said “if someone isn’t improving, we know right away. If someone is plateauing, we know from the database. People are definitely served poorly in the state, wrongly placed...we took some kids recently with no communication, not toilet trained...kids are not being served as well as they should be” (J, 1/18/13). There are also grants and scholarships to send children to this school and children in New Jersey and surrounding states who have been diagnosed late in life and who benefit from the education they get at this school. They get jobs, learn how to use tools, have recreational
facilities, and some of the best technology. Another school in the Philadelphia area offers the same, although the waitlist is much larger because of the number of children who are diagnosed simply in the city.

As Stanley Greenspan, who founded the Floortime method, says, “don’t pressure yourself to do so much. Whenever you feel stuck, take a step back, relax, and observe what the child is doing. The child may not seem to be doing much; she may just be playing with her own fingers. But that is something. A child is always doing something. Ask yourself how you can build on it” (Greenspan, 2006: 184). Although this quote does not reflect the purpose of his book, I think this is a really important point because so many parents struggle to just take a step back and think beyond autism being their fault and learning how to serve their children in the best way possible.

How Can We Help?

Rather than put parents at fault for autism or blaming them for not being able to acquire resources, there are many things that we can do to help the parents cope with their child’s autism. It is the responsibility of our society “to accommodate neurodiversity,” (Sharpe, 2007: 250) which means that we must accommodate the needs of children with autism in better ways. We have to start thinking about the ways in which we can work with families to make their lives easier.

Many practitioners are already starting to try to work with families. One organization that works predominantly with low-income and inner-city families has “hired parents who have children with autism to go through the system to work with the staff and become staff to work with other parents, because our staff couldn’t understand the needs of parents and parents couldn’t understand the system.” (M, 1/15/13) They recognized that the staff is not always as
trained as parents who have been through the autism and live it each day of their lives, and many of the staff are also coming from White neighborhoods. They also are not well-versed in autism first hand. Even parents agree that there has to be some network of parents who are support (F, 1/11/13) so that they can communicate with each other about their own struggles. Practitioners often forget about the struggles of families who are going through this with their children.

Practitioners also often forget that there are differences in families, particularly high-income versus low-income families, and make assumptions about what families can afford and also about their beliefs that may affect the way in which autism should be handled. As Welterlin says in her article, “Practitioners must conduct a thorough assessment before assuming a family’s values, beliefs and practices” (Welterlin, 2007: 750). Parents always need extra support, and this could help parents to understand that practitioners respect their differences and are willing to work with them so that their children can get the best care. Service providers must recognize and respect the value systems of others so that they can learn how to help child with autism (Harry et al, 1999: 133). Many practitioners are not working with parents as much as they should be.

There are also therapists who only work with the child and not with the parent(s). As one therapist said, “I also don’t like therapists who work in isolation...they’ll work with child but not everyone around the child, and I am also worried when people diagnose kids and don’t reach out to everyone working with child” (E, 2/22/13). E is a therapist and consultant for families with children with autism and specializes in high-functioning autism. This could be extremely important for parents coming from lower-income and a different culture because the parents may have their own ideas about what is best for the child. This could also help to build up trust between the parents and the therapists since there is already not much trust between the two groups. Working with parents could also help them to understand what autism is, which is
extremely important since they will be living with and working with the child. In this way, manipulation will also be decreased from the therapists. Along those lines, "...service providers need to be familiar with how the personal, interpersonal, and community planes of development interact for any individual" (Harry et al., 1999: 133). Low-income communities don’t have the same sort of community partners that other higher-income groups may have, and service providers need to recognize those differences and be able to give the proper support based on how the family interacts with the community.

Programs must also be sympathetic towards the differences between families with a child with autism. As one program administrator says, “this program is about your child...we really look at the social component of it...” (N, 2/25/13). They recognize that the best way to help the child is to look at the social components of working with a disability and also how the status of the parent is extremely useful to working with the diagnosis. N is extremely patient with parents and works with them individually and in groups so that they can learn from him and also from each other.

This relates also to practitioners teaching the parents about autism and telling them what autism is. They must help parents understand what autism is. As one clinician in Philadelphia who works with children, B, reported, we have to help parents understand what autism is, and he has seen parents come in “who just don’t understand what autism is.” B primarily works with parents to figure out the best treatment plan for their children and has also done research in other positions.

Next, the support system of other parents, whether or not they know what autism is, must learn how to be sympathetic and understanding towards the parents of children with autism. They should be able to offer help, instead of trying to act as if they understand the struggles of
raising an autistic child (Whiffen: 2009, 27). Parents need the support from their network of other parents.

Finally, the school is a great place to get the support. Schools must be able to educate the other children about all disabilities, and they should start to have lessons on how to interact with children with autism. Bullying should be written into the IEPs as recommended by K who is a professor and director of a program for children with autism in Philadelphia. One parent also said that “good schools and good teachers are essential” (G, 1/12/13) as well as a strong family and friend network.

Many parents lose hope for their children in the fight against autism, but “hope is the most critical element in fighting autism” (Ariel, 2006: 83). If parents believe that their children can succeed past doctor’s beliefs, then the child will ultimately become better. Many parents also begin to see autism as a, “blessing that prevents you from ever taking your child’s laugh, embrace, or verbalization for granted” (Ariel, 2006: 83). Autism is intense and invasive, and there isn’t always support for parents. However, they love their children, and as a society, we need to be able to work with them. “We love each other and we learn to sacrifice a lot” (N, 2/25/13).

_Closing Thoughts_

I want this paper to be a way for parents to feel less guilty. All of the parents I talked to have done so much to help their children, and the therapists and administrators who I got into contact with definitely are working everyday through their love and appreciation of parents to try to make autism treatment easier. Work on autism can make a difference and I want this paper to make a difference for the community of people with autism. All parents are extremely different
in the ways that they approach diagnosis and treatment. With this anthropological perspective on abuse and care, guilt and shame, and the relationships that caregivers have with children, this paper can offer insight into how clinicians can continue treatment of autism and also how parents can learn not to give up and to never say never.
Bibliography

Primary Sources

Interviews

Lectures

Blogs
AspergersMom, Karen

Gorski, Rob
Lost and Tired, http://lostandtired.com/

Senator, Susan
Susan Senator’s Blog, http://susansenator.com/blog/

W, Jim

Secondary Sources

Books
Adams, Christina

Ariel, Cindy ed.

Barnbaum, Deborah R

Baron, M. G.

Baron-Cohen, Simon.

Barron, Judy and Sean Barron

Bérbé, Michael
1996  Life As We Know It: A Father, a Family, and an Exceptional Child. New York: Pantheon Books.

Bierens, Francesca.

Chrisman, Noel J. and Thomas M. Johnson.

Cohen, Shirley

Cumberland, Debra

Dixon, Nicholas

Dougherty, Phil.

Edgerton, Robert B.
Ernsberger, Lori.

Foucault, Michel

Foucault, Michel

Goffman, Erving.

Goffman, Erving

Grandin, Temple.

Grandin, Temple and Margaret Scariano

Greenspan, Stanley I.

Hewetson, Ann

Hillman, Jennifer with Stephen Snyder and James A. Neubrander

Inhorn, Marcia and Emily Wentzell, eds.

Jenkins, Janis H.

Kleinman, Arthur.

Laing, Ronald D.

Landsman, Gail.

Linton, Simi

Marshall, Patricia A. and Barbara A. Koenig

National Institute of Mental Health.

Nazeer, Kamran.

Nelson, John.

Notbohm, Ellen.

Nussbaum, Martha C.

Osteen, Mark, ed.

Osteen, Mark
Phillips, Sarah D.

Quill, Kathleen Ann, ed.

Rapp, Rayna and Faye Ginsburg.

Rawls, John

Sargent, Carolyn F. and Thomas M. Johnson, eds.

Schreibman, Laura E.

Senator, Susan

Silverman, Chloe.

Szasz, Thomas

Whiffen, Leeann

Zager, Dianne, ed.

Zelizer, Viviana A.
Academic Articles

Bagatell, Nancy

Bailey, Donald with Debra Skinner, Patricia Rodriguez, Dianne Gut, and Vivian Correa.

Bourdieu, Pierre

Chandler, Susie with Philip Christie, Elizabeth Newson and Wendy Prevezer

Chipres, Lourdes.

Dubay, Lisa and Genevieve M. Kenney

Dyches, Tina Taylor, with Lynn K. Wilder, Richard R. Sudweeks, Festus E. Obiakor, and Bob Algozzine

Fox, Lise with Glen Dunlap and Leigh Ann Philbrick

Harry, Beth with Robert Rueda and Maya Kalyanpur.

Hebbeler, Kathleen with Donna Spiker, Don Bailey, Anita Scarborough, Sangeeta Mallik, Rune Simeonsson, Marnie Singer, Lauren Nelson
Hughes, Bill.

Mandell, David with Maytali Novak, and Cynthia Zubritsky

Mandell, David with Lisa D. Wiggins, Laura Arnstein Carpenter, Julie Daniels, Carolyn DiGuiseppi, Maureen S. Durkin, Ellen Giarelli, Michael J. Morrier, Joyce S. Nicholas, Jennifer A. Pinto-Martin, Paul T. Shattuck, Kathleen C. Thomas, Marshalyn Yeargin-Allsopp, and Russell S. Kirby

Mandell, David with Knashawn Morales, Ming Xie, Lindsay Lawer, Aubyn Stahmer, and Steven Marcus

Morrier, Michael and Kristen Hess.

Ochs, Elinor with Tamar Kremer-Sadlik, Karen Gainer Sirota and Olga Solomon

Palmer, Raymond with Tatiana Walker, David Mandell, Bryan Bayles, and Claudia Miller.

Rapp, Rayna and Faye Ginsburg.

Rapp, Rayna and Faye Ginsburg

Schopler, Eric and Robert J. Reichler

Schreibman, Laura E.
2000 Intensive behavioral/psychoeducational treatments for autism: research needs and future

Sharpe, Deanna and Dana Lee Baker.
2007 Financial Issues Associated with Having a Child with Autism. Journal on Family and

Skinner, Debra with Donald Bailey, Vivian Correa, and Patricia Rodriguez.
1999 Narrating Self and Disability: Latino Mothers’ Construction of Identities vis-à-vis Their

Solomon, Olga
2010 Sense and the Senses: Anthropology and the Study of Autism. Annual Review of

Thomas, Pauline with Walter Zahorodny, Bo Peng, Soyeon Kim, Nisha Jani, William Halperin
and Michael Brimacombe.

Waltz, Mitzi.
2005 Reading case studies of people with autistic spectrum disorders: a cultural studies

Welterlin, Aurelie and Robert H. Larue.
2007 Serving the needs of immigrant families of children with autism. Disability & Society
22(7): 747-760.

Wilder, Lynn K. with Tina Taylor Dyches, Festus E. Obiakor, and Bob Algozzine
2004 Multicultural Perspectives on Teaching Students with Autism. Focus on Autism and
Other Developmental Disabilities 19(2): 105-113.

Newspaper Articles
Carey, Benedict
2013 Some With Autism Diagnosis can Overcome Symptoms Study Finds. New York Times,
January 16.

O’Connor, Anahad

Pilkington, Ed

Films
Horn, Elizabeth, dir.
2007 Finding the Words. 60 min. Horn Productions.
YouTube
2012 Footage of Judge Rotenberg Center torturing a person with a disability aired in court.

Online Newspaper Articles
AlHajal, Khalil

Chew, Kristina

Finney, Karen

Gillette, Hope
? Hispanic children with autism remain undiagnosed, reveals study.

Waltz, Mitzi
2011 Identifying autism in children from ethnic minorities.

Wood, Janice
2012 Development Delays, Autism Often Missed in Hispanic Children.
Appendix A: Interview Questions.

1. What is your role as an educator/counselor/trainer/therapist/administrator? Could you describe your central responsibilities? FOR PARENTS: how old is your child? When was he/she diagnosed?

2. What issues have you encountered in the work you are doing? FOR PARENTS: what were you feeling/thinking when your child was diagnosed? Did you already have an awareness?

3. What are some of the symptoms of autism?

4. If an educator or education administrator: What problems have you run into in the workplace? Is there a certain curriculum you use? How does your work change with autistic children? What is the difference in working with autistic children? What sort of routine do you use? What forms of communication do you use? How have you formulated your teaching environment? How do you work with behavioral issues?

5. If a counselor, therapist, or trainer: What are the differences in working with children on the autism spectrum from children who are not on the spectrum at all? Do you think there are children who are wrongly diagnosed or who are not diagnosed at all? Have you seen increased rates? If so, why do you think that is? What advice do you give to parents? What forms of communication do you advise? What forms of treatment (therapists/trainers only)? What forms of treatment do you use (therapists/trainers only)? What questions should parents ask when figuring out a treatment plan?

6. If a parent: What resources have you tried using to work with your child? Have they been helpful? What part of the spectrum does your child fall on? What is life like at home with the child? What sort of challenges, if any, have you faced at home/school/public places? How do you sense a change in mood? What sorts of emotional challenges have you had? How does your child best communicate? Does a change in routine affect behavior? Have you tried different sorts of therapies – what has worked?

7. Are there any ethical challenges you have faced? For example, in times of frustration, you don’t want to blame your child because you know that they don’t always understand what they did wrong, or as a teacher, you don’t know how to tell the child that they did something wrong? Or, have you ever felt guilty because you don’t feel like you have done enough?

8. Have you seen a lot of bullying? How do you/families approach it?
9. Are there differences between working with lower-income families versus higher-income families? Immigrant versus non-immigrant families? PARENT: do you think your income affects (betters/ worsens) the way you can obtain resources for your child?

10. How has the child socialized with other kids? How have you observed children with autism socialize?

11. Do you think that it is possible for children to recover? What does recovery mean/ look like to you? Is there a treatment that works well in general or more so than others?

12. What sort of treatment has worked best for the child? What do they seem to enjoy? Are there financial issues to receiving care?

13. Do you ever feel as if your child is not receiving the best care? Are there issues with receiving care?

14. What sorts of things should not be said to a child with autism or someone who works with a child with autism?

15. What sorts of tips have you heard from other people in working with an autistic child “because it works for other children”?

16. How do families with a child with autism bond?
Appendix B: E-Mail Recruiting Script.

Dear __________,

My name is Lisa Sendrow, and I am a senior at Swarthmore College. I am conducting a research project on the challenges of autism, and I am interviewing around 20 involved parents, teachers, therapists, and program administrators to get a range of perspectives on the challenges related to autism concerning treatment, socialization, and communication.

I would like to invite you to contribute your experiences by participating in an hour-long audio-recorded interview - either over the phone or in person at any time and place that is convenient to you. The general topics would be what types of treatments you have experienced, what challenges autistic children face in different settings, how they interact with others in the school and in the home, and what advice you have received and would give to others. I would discuss and quote your interview in my senior thesis, but I would make every attempt to maintain confidentiality by changing all names of individuals and organizations as well as any other potentially identifying details in my writing.

If you are interested in participating, please contact me at lisa.sendrow@gmail.com or 609-610-5763. I am hoping that my project can reveal some new information about how to best help autistic children, and how as a community we can work together to ensure that autistic children have the best life possible.

Sincerely,
Lisa Sendrow
Appendix C: Informed Consent Form

I would like to invite you today to participate in a research study about the challenges of autism. The purpose of my research is to explore the different ways in which we treat autism, and to learn about the problems faced by autistic children in different areas of life. I anticipate interviewing approximately 20 people for this project, with parents of autistic children as well as professionals who are involved with them.

I am proposing to audio-record an hour-long interview where I ask you some open-ended questions about the challenges autistic children face with treatment, socialization, and communication. I will be transcribing the interview and then discussing and quoting it in my thesis, but I will make every attempt to maintain confidentiality by changing all names and altering or omitting other potentially identifying details. I will be keeping all my files encrypted on my laptop, without your name or email connected to them. I will only be using your interview for my thesis research, and once it is finished I will be destroying all the records.
If you agree to participate, it is entirely voluntary, and you have the right to skip questions, discontinue or withdraw from participating at any time without penalty. You are also free to decide at any time that you don’t want your interview to be used after all, and I will destroy it along with all other records mentioning you.

There are no direct benefits to you for taking part in my research, but I am hoping that your contribution will help advance understanding of the challenges of autism. I am not expecting the interview to be unduly stressful, although we will discuss important issues and problems may be close to you. If you become uncomfortable, please let me know and we can stop. You may of course say something that could affect your relationships with friends, colleagues, and employers if confidentiality is breached, but the questions are not intended to elicit damaging information, and procedures to maintain confidentiality will be followed as outlined above.

If I have answered all your questions and you agree to participate, please sign below. By signing below you agree to be at least 18 years of age. If you have any questions or concerns about the study, contact Lisa Sendrow (at 609-610-5763 or lisa.sendrow@gmail.com). If you have any questions about your rights as a human subject, please contact the Swarthmore College Institutional Review Board at IRB@swarthmore.edu or 610-957-6150.

Name of Participant (please print):

________________________________________

________________________________________

Participant Signature Date
Appendix D: Verbal/Telephone Consent Script.

Before starting and recording the interview I want to make sure that you know what my research is about, what I’m asking you to do, and what risks and protections are involved. To do this I’m just going to run through the information I sent you earlier by email:

************************ Script to be Emailed *************************

Educational Programs and the Impact on Childhood Autism

A Senior Thesis Research Project in Sociology and Anthropology
College

Conducted by Lisa Sendrow, undergraduate senior

IRB Protocol Number: 12-13-011

The purpose of my research is to explore the different ways in which we treat autism, and to learn about the problems faced by autistic children in different areas of life. I anticipate interviewing approximately 20 people for this project, with parents of autistic children as well as professionals who are involved with them.

I am proposing to audio record an hour-long interview where I ask you some open-ended questions about the challenges autistic children face with treatment, socialization, and communication. I will be transcribing the interview and then discussing and quoting it in my thesis, but I will make every attempt to maintain confidentiality by changing all names and altering or omitting other potentially identifying details. I will be keeping all my files encrypted on my laptop, without your name or email connected to them. I will only be using your interview for my thesis research, and once it is finished I will be destroying all the records.

If you agree to participate, it is entirely voluntary, and you have the right to skip questions, discontinue or withdraw from participating at any time without penalty. You are also free to decide at any time that you don’t want your interview to be used after all, and I will destroy it along with all other records mentioning you.

There are no direct benefits to you for taking part in my research, but I am hoping that your contribution will help advance understanding of the challenges of autism. I am not expecting the interview to be unduly stressful, although we will discuss important issues
and problems may be close to you. If you become uncomfortable, please let me know and we can stop. You may of course say something that could affect your relationships with friends, colleagues, and employers if confidentiality is breached, but the questions are not intended to elicit damaging information, and procedures to maintain confidentiality will be followed as outlined above.

If you have any questions or concerns about the study, contact Lisa Sendrow (at 609-610-5763 or lisa.sendrow@gmail.com). If you have any questions about your rights as a human subject, please contact the Swarthmore College Institutional Review Board at IRB@swarthmore.edu or 610-957-6150. You must be over 18 to take part in the study.

******************************************************************

Does all this seem clear? Do you have any questions?

Can I now start recording?