



## Black Autistic Lives Matter

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### Introduction

The political atmosphere in the United States has been rife with questionable police behavior, the death of Black men, and general mistrust between communities and the local (and some would say, national) authority. We have heard the cases of Trayvon Martin, Freddie Gray, Tamir Rice, Michael Brown, Eric Garner, and many more. Though many Black men have died in the past decade due to police brutality and excessive force, Freddie Gray stood out. The Baltimore Sun published an article entitled, "Why no talk about Gray's disabilities?" This article bemoaned the little detail given to Gray's early childhood, which was harmed by his exposure to lead. The lead poisoning resulted in neurological damage, learning disabilities, and delayed developmental growth, which ultimately meant many social and communication challenges [1]. So why such little mention about Gray's disabilities? There are many potentially reasons: stigma in the Black and greater communities, ignorance of what able-ism means for a person of color, challenges deciphering between racial and ability bias, and the list could go on. However, though this opinion piece will not be able to answer the question posed by Zosia Zaks, author of the article, it will explore autism in the Black community, specifically from one autistic man's perspective Joseph Adewale [2].

### Joseph Adewale

Joseph Adewale was born October 13th, 1980 to parents Benjamin and Leslie Adewale. With the birth of their first child came many celebrations as well as challenges. At 3 years of age Joseph was diagnosed with moderate to severe mental retardation and autism spectrum disorder. Like many parents who first hear such a diagnosis, shock turned to feverish researching and second opinions. However, after the third exact diagnosis, the family accepted Joseph's condition, and Leslie began looking into ways to make Joseph's life easier.

Thirty years ago, at the time of Joseph's diagnosis, there were few resources and accommodations for those with autism or mental retardation. Because of this, Joseph was mainstreamed in elementary school with additional speech therapy (which was paid for out of pocket due to lack of insurance coverage). By the time Joseph was nine years old, Dr. Benjamin Adewale had a new job, which prompted the relocation of the small family to the DC/Virginia area. It was there they found Key Center, a school that supports and promotes the development of those with cognitive disabilities. Joseph was able to thrive in this environment. He was taught basic vocational skills such as stuffing envelopes, washing dishes, wiping tables, and more. Since Key Center collaborated with many outside organizations, students were able to practice these skills in actual work settings (Meals on Wheels, Walmart, and other organizations collaborate with schools like Key Center to promote inclusion).

Joseph finished at Key Center at age 22. His graduation marked several milestones: his parents' successful maneuvering of the legal

system (which was necessary in order for them to remain his guardians when he turned 18), stable medication management for his behavior outbursts, and completion of an 8 week stay at the John Hopkins Kennedy Krieger Institute for a behavioral therapy program. The entire Adewale family, which now included 2 more children, celebrated Joseph's accomplishments.

Neither autism spectrum disorder nor his moderate to severe mental retardation has stopped Joseph from achieving several goals. However, there were still many issues facing the Adewale family. Joseph now stands at 6'0" and weighs 190 lbs. He often can pass as a "regular" 34 year old man when seen on the street though doctors say socially he is a 4 year old while his basic learning skills make him equivalent to a 5 or 6 year old. Though Joseph can use the bathroom on his own, his speech is predominately echolalia, and his obsessive-compulsive disorder makes it hard for him to receive tactile stimulation.

Though he found solace at Key Center, many people did not accept him. Community members often looked at his disabilities and questioned why anyone would "let him out". His size and blackness often made people uncomfortable, something Leslie attributes to ignorance. Because of this, Joseph is never left alone for fear that someone may mistake his harmless laughter or melodic humming as threatening. He is an extremely remarkable young man in a less than remarkable setting. Without the support of his family and friends, his life experiences would have been muddled with even more challenges and gaps of care.

In the next 6 case studies, different situations have been outlined. These situations are just snapshots into the successes and challenges that Joseph and his family have had to face. Some of these situations are exacerbated because he is a Black man living in the United States, and others are the day-to-day lives of others living with autism and other cognitive disabilities.

## Navigating the Healthcare System and Beyond

### Case Study 1: Group Home Abuse

In 2006, Joseph moved from living with his family to a group home with 4 young men (2 of the men have autism while the other are moderate to severely mentally retarded). All 5 of the men have varying functioning levels. The group home setting can be an extremely positive and supportive environment for those with cognitive disabilities [3]. Most group homes of this type have ample supervision and workers. However, within the first few months of living in the group home, Joseph experienced a medication error that could have been avoided.

Joseph takes Depakote sprinkles in combination with other medications to control his behavior. These pills must be broken and sprinkled over food in order for him to take them. During a family

visit, Leslie noticed the worker, who was trained in medication handling and management, simply handing Joseph his medication without any of the necessary preparations. Since Joseph cannot swallow pills, he was simply chewing them. This medication error was quickly corrected, however it was soon uncovered that another young man on the same medication (who had been in the house even longer) had also been taking it incorrectly for years. In comparison to other stories at this house, Joseph's situation is minor.

There have also been issues with trust between caregivers and parents. It is extremely important to be able to trust the people taking care of your loved one with autism, however often times this trust is abused. Joseph has been hit, fed extremely fatty and innutritious foods, as well as nearly left at the mall during an outing. If it was not for the continuous attention given by Joseph's family, more misconduct could have occurred. In most of these situations, the worker has been asked to transfer to another group home. When did it become okay to treat people with autism so poorly? These are instances we see inequality in standards of care.

### Case Study 2: Case Management Needs

Case management work can be helpful for people dealing with chronic illnesses or disabilities by ensuring that all the appropriate services and resources outside the clinical setting are harnessed. Joseph has benefitted from case management for many years. Leslie's frequent meetings with social workers and case managers always include next steps to improve Joseph's life.

Case management for a person with different cognitive abilities is critical, especially during the transition between pediatric and adult life [4]. In the past, Joseph's case managers have helped pushed important Medicaid requests and waivers through, create ISPs (individual support planning), settle group home issues, and locate important behavior and medication resources. However, when it comes to people with autism, finding stable and effective case management is difficult. In Joseph's life, he has had 4 case managers. He was fortunate to have one person for decade, and usually he gets placed with different people every 2-3 years. Case management workers in this setting face extreme workloads, tight time frames, and limited budgets. Like many people with autism, Joseph needs consistency. As soon as he gets acquainted with one case manager, he is switched to a new person. This lack of consistent care yields gaps in care-coordination and missed resources.

### Case Study 3: Underinsured

Joseph starting receiving disability benefits when he turned 18. Similarly, when he entered adult-hood, his insurance switched from his parent's to Medicaid. Approximately 65 million Americans use Medicaid [5]. Currently, Medicaid covers Joseph's day program, which allows him to do to volunteer work in the community, his medication, and basic medical needs, with the exception of medication packaging (Joseph's medication comes in special bubble packaging to help group home workers proper dosage).

There are 2 major instances in which Medicaid has not been enough. Dental health is not covered for Joseph. In order to have any type of oral health covered, Joseph must have exceptional dental needs. Currently, Joseph deals with mild to moderate gum disease (due to lack of flossing at his group home). He requires regular dental check ups, which are paid for, out of pocket, by his parents.

The 2nd instance involves speech therapy. In the past, Medicaid has agreed to pay for 2 speech therapy sessions a week, while Leslie and Ben paid for an additional 2 speech therapies (totaling 4 sessions a week). Generally Joseph is non-verbal except for some echolalia. Medical doctors have suggested and encouraged speech therapy in order to improve Joseph's communication skills [6]. Four years ago, Medicaid stopped subsidizing speech therapy sessions due to "diminished funds". In addition to speech therapy, behavioral therapy sessions also ceased. For these past few years, Leslie and the case managers have been fighting to get these critical services back into Joseph's life.

### Case Study 4: Medication Madness

Joseph takes several different medication combinations (8-10 different medications as of 2015). His liver and kidney functions have yet to be checked with such a heavy drug load, and potential drug interactions are often times not considered. In addition, people with autism and other cognitive disabilities often have their general health forgotten. His medication is often changed without sufficient monitoring or thought to other complications. And recently, Joseph has been diagnosed with Type 2 diabetes, something that has made his current situation even more difficult.

Implicit bias can be a major issue in medicine [7]. We often times think of racial bias, where physicians can treat patients of different racial backgrounds presenting the same exact symptoms in totally different ways. People of color are either misdiagnosed or under diagnosed due to the implicit bias of a physician. This extends to those with disabilities, and furthermore complexes when race is also considered. Many times people with autism are described as having special needs, and sometimes that is the case. However, in most situations, people with autism and other cognitive disabilities need the basic needs. They need to be treated at the same standard of care as others are. Joseph deserves careful medication monitoring and consideration. He deserves proper chronic disease screening and yearly well checks. Autism does not lessen his risk for other health related diseases.

### Case Study 5: Work and No Pay

At Joseph's day program he does anything from wash dishes, take out the trash, stuff envelopes, and more. Three years ago, he was paid minimum wage for the exact same work he was doing while enrolled in a work program. Due to lack of funding, this work program was cut and he was demoted to a day program. There are many benefits to this day program: Joseph continues to be in the community, he keeps busy day to day, and he continues to hone his social and work skills. However, there are few people who would continue doing their job if their funding was cut, yet Joseph and many others in this program are working and contributing without proper compensation.

After room, board, and food, Joseph has 25% left of his disability payment. This has proven not enough for basic life necessities and activities. Fortunately, Joseph still has his parent to supplement his income. They add money to his account to pay for additional meals, new clothes, toiletries, and more. For others without an income supplement, the food bank and local clothing closets are the only resources they have.

## Case study 6: Breakdowns in Family-Community Support Networks

Autism in any community can be confusing, threatening, and generally frightening. In recent years, society has taken steps in the positive direction when learning how to address the needs of those with cognitive disabilities. In African American communities, the response to autism has been slower. Generally, due to the strong presence of religion, African American and other religious communities will be more accepting of those with disabilities, however some of most common comments that Leslie received when attending church were: “you must have done something wrong in your life”, “God must be punishing you for something”, “If you pray hard enough, it will go away” [8]. Despite these barriers, the Adewales found a church home that not only accepted Joseph but also had a Sunday school department suited for people with cognitive disabilities.

Cultural issues have always been a concern in addressing Joseph’s issues. He comes from a family that is both Black American and African. Dr. Benjamin Adewale was born and raised in Nigeria. He came to the United States to go to college and medical school. While Leslie Adewale was born and raised in Houston, Texas, with a family line directly stemming from enslaved people. Often times in West African culture, people with cognitive disabilities are thrown away or forgotten due to the little resources to address their needs [9]. Many people do not know how to interact and include those with disabilities and therefore they do not try. Though Joseph has strong family and community support, there are always gaps and difficulties. As many families with loved ones with autism have experienced, there are always some family members that do not seem to know how to connect. With communities, there have been wonderful times that community members have embraced Joseph, outbursts and idiosyncrasies in all, however there are some that have been frightened by the Black autistic man and pushed him away.

## Next Steps

But why does this all matter? And what can the political atmosphere dictate to the medical community? There are many interests in health equity and healthcare for all. Unfortunately, equity concerns in the United States have continued to leave out several groups including those with cognitive disabilities, people of color, and the population that spans both categories. The United States recently expanded its healthcare coverage with the Affordable Care Act, however healthcare coverage does not transform all of the issues of access or physician biases against certain patient populations (though it helps with some the issues that uninsured/underinsured Americans were facing). By looking at Joseph’s pediatric and adult life, we see that it has been riddled with challenges due to the fact that sometimes people with

autism are treated poorly. Joseph being a Black male continues to add even more challenges to his life. Using the experiences outlined above can benefit research [10].

In Zaks’ article, she calls for the education and training of police and law enforcement personnel. She is currently the manager of programs and education at Towson University’s Hussman Center for Adults with Autism, and daily she uses the very skills she wants police officers to have, with adults with varied developmental and functioning abilities. She insists that proper training to respond to autistic adults does not mean holding them accountable to a different standard of law, on the contrary, people with autism must be held to the same standard of law as anyone else. What is different is the addition of certain accommodations, support systems, and attention given in order to level an extremely uneven playing field. The same should be proposed for the medical and healthcare community. Social workers, providers, community members, and insurance stakeholders should be poised with the right tools to better address the needs of those with autism, especially when that person is a minority.

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