**SEMESTER 2 ESSAY**

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**Question 2 A-WHAT IMPACT DOES THE ARTIST AS A CELEBRITY HAVE?**

**INTRODUCTION**

Representation of marginalised groups in media is often a complicated and controversial topic. Neurodiversity and in particular autism, are often misrepresented by organisations and celebrities who believe it is something that needs to be cured and or “celebrated”. The problem with this is that many of these organisations, like Autism Speaks, spread misinformation on the matter and do not involve the people they say they represent e.g. people who are on the autistic spectrum. Organisations like Autism Speaks approach big names like Yoko Ono to raise funds for their “cause” and backing projects by celebrities such as SIA when making anything that relates to the topic of autism. The artists themselves do little to no research on what the organisations they are supporting do, spreading misinformation in the process.

This essay will tackle the controversies of organisations like Autism Speaks, and how they mis-represent the groups they say they advocate for. I want to bring to light the harmful impact celebrities like Yoko Ono and SIA have when trying to represent autistic individuals in their work through the backing of organisations such as Autism Speaks. How do these celebrities perpetuate these messages in relation to autism? Where have they gathered this information? And why are they spreading the idea that autistics are not able to represent themselves?

SIA and Yoko Ono have no personal connection to autism so why do they believe they have the right to speak for those on the autistic spectrum, rather than listening to their voices instead?

When it comes to the representation of marginalised voices the questions lie within who should speak for whom?

Should a celebrity with no personal connections to autism be speaking on autistics behalf, or should autistic individuals speak for themselves?

**REPRESENTATION OF MARGINALISED VOICES**

This is the problem of representation of marginalised voices: the argument of who has the right to speak, those from their own personal experiences being autistic, or those who know someone on the spectrum and their own experiences in that regard.

Does a parent who believes that autism is an illness and therefore should be cured, speak on their child’s behalf?

Or should the child speak for themselves being autistic, and their own experiences when regarding the opinions/choices made concerning their lives?

Organisations like Autism Speaks choose to voice their experiences and opinions over that of the autistic individuals they say they are representing. Autism Speaks mission is to find a cure and prevention of autism believing that those with autism cannot speak or advocate for themselves. They enhance the voices of the parents, guardians and care-workers who they say are burdened with said autistic individuals (Crossman, 2019).

On the Autism Speaks board of twenty-eight directors, only two are autistic. twenty-one of the board members are former/current executives and CEOs of big corporations such as, GAP, Paypal and Goldman Sachs, so why is it that they can speak on the behalf of autistics, but the Autistics cannot speak for themselves?

This issue is why groups like ASAN (Autistic self-advocacy Network) and ‘Communication First’ now exist (ASAN, our history). These groups are primarily made up of and enhance the voices of autistic individuals.

Self-advocates on the other hand are individuals speaking from their own experiences growing up on the spectrum. Whether this is an adult who has been has been recently diagnosed, and the revelations they can now make and connect to problems growing up. Or voices of those who have grown up in families who went to organisations like Autism Speaks, and now have repressed trauma due to the therapies they recommend will “cure” their child, like ABA (Applied Behaviour Analysis) therapy (Raeburn, 2016).

So why is it that groups like Autism Speaks get recommended and overshadow other groups and individuals with an autistic perspective themselves?

Autism Speaks is known as the largest autism charity worldwide, known for working with many celebrities who support and enhance their messages, despite their controversial marketing, eg “I Am Autism” advert (ASAN, 2009)

Autism Speaks does little to no support for families with the funds they raise, less than 4% goes to improving quality of life, 32% going towards research purposes, most of which have been devoted to the cause and prevention of autism. Even some salaries for their employees exceeding $395,000, whilst having no prioritised funds or budgets for the practical supports and impact for families (Rootpolicy.com).

Yoko Ono’s Comission

The Celebrities they have worked with have no regards to what they are actually supporting, and this is a classic example of the “celebrity soul” (Littler,J. 2008), where misinformation and horrifying messages are being sent and spread by celebrities sympathising with issues they have not put their own research into and organisations causes/goals they are supporting without question. This influences their audiences with these messages, and therefore groups like Autism Speaks are recommended over that of organisations like ASAN.

Autism Speaks is aware of this influence and have exploited this in approaching celebrities themselves for fundraisers in the past.

In 2007 Autism Speaks commissioned Yoko Ono to create artwork that could be sold to raise funds for their cause. Yoko Ono is known as the mother of performance art and was married to the John Lennon. She has supported many causes over the years with her art and public influence, so knowing this Autism Speaks commissioned Yoko Ono knowing she would support them no questions asked. Soon after this, Yoko became the first Autism Speaks “Global Autism Envoy”, but nowhere is it stated she has or is connected to somehow to autism in any other regards (The Japan Times, 2010)

Through her influence she has raised funds for Autism Speaks over the years and has even got in New York Empire State Building to “light up blue” (CBS New York, 2013). This perpetuates the idea of Autism being a “male” condition, upset with this the actually autistic community came up with the hashtag “red-instead”. Made in retaliation to this stereotype on autism being strictly a “male” condition using red, a gender-neutral colour, to counteract Autism Speaks’ message. By supporting Autism Speaks, Yoko Ono is enhancing negative prejudices and stereotypes in her continuing support.

By creating this artwork Yoko Ono has stated her belief of what she is supporting, that autism is something that is in need of a “cure”, whilst showing no outside research into what she is raising funds for believing the ideals that Autism Speaks is for.

Yoko Ono’s artwork is that of 69 puzzle pieces, with the idea that the number of pieces is to represent how many people worldwide have autism. In a BBC article she stated (Lane,T. 2009)

“*Once the solutions for Autism is discovered, we will see the sky shimmering in its original beauty, with no holes.”*

Showing again that outside of Autism Speaks support, there was no outside research with autistic individuals’ perspectives put into her artwork before making it.

Yoko Ono’s artwork perpetuates the negatives associated with autism. The puzzle piece narrative is one that many autism organisations and charities use, in their logos and marketing, usually when they are not voiced by autistics themselves.

It was first used in context with autism by Gerald Gason of the National autistic society Uk in 1963. Depicting a weeping child superimposed on the puzzle piece, reinforcing the idea that something was “a-miss” in the child. Professionals at the time felt this was “fitting” due to the puzzling nature of the condition (Crossman, C. 2019).

This shows that from early on its association to autism was negative, and even perpetuating the idea of wrongness with the condition. Nowadays, organisations like Autism Speaks use this as their main symbol, which continues to invoke negative associations about autism through the imagery of solving autism (Gernbacher,M. 2018).

 Outside the narrative of autism, there was a study about the idea of the puzzle piece and negative associations. In the study even when removed from the context of autism, the imagery of the isolated lone puzzle piece, invoked emotions of uneasiness in the general public.

This again shows again that Autism Speaks and Yoko Ono’s choice of the puzzle piece visual in their work, in relation to autism continues to influence the general public’s view of autism itself.

A

**THE SIA DEBACKLE**

A recent event that showcased the negative portrayal of autism in media is that of the popstar SIA and her recent movie MUSIC. When it was announced it was still in production, and no one knew what movie was about, until its official announcement last November.

SIA described the film as a “love-letter” to the autistic community, and that it showed support to the care workers and families of those who are autistic. SIA boasted on twitter about doing three-plus years of research before making this film in 2017, though she got this research and funding from none other than Autism Speaks themselves(Harring,B 2020).

Although SIA said this was made with good intentions, when you look at the individual aspects of the films from casting, scripting to production, what about these “good inte’’ntions” was good?

SIA said she was inspired by an individual she met during rehab, who was autistic, but the way Autism is used in the film says otherwise.

The autistic character and her “magical view” into the world, was an excuse to insert SIAs music into the film. Outside of this the film never focuses on the autistic character’s perspective (Leary,A 2020).

In place of a neurodivergent autistic actor, SIA’s muse Maddie Ziegler, starred in the film. After its announcement the autistic community was outraged at this, and although SIA tried to placate fans by saying there was originally an autistic actor who found the job “too stressful”. Now if this was the case why couldn’t SIA and her team make the environment accessible for the autistic actor in a movie meant to represent autism?

Evidence from past interviews counteracts that during the making of the film Sia states herself that she wanted to work on and showcase Maddie in a movie project of her own, showing that there was no autistic actor in the first place. After the backlash of being caught out on this lie SIA insulted and attacked those on Twitter who were not happy about this decision(Ntim,Z, 2021; Rocca, J 2020)

SIAs view that non-verbal autistics could not represent themselves was enhanced by an interview where she agreed that nonspeaking autistics may as well be inanimate objects (like wigs) to be worn in used in productions for creative uses. After the backlash from the autistic community SIA retaliated by saying non-verbal autistics couldn’t say how good of a job she did (Courtney,2021; Mikayla, 2021; Breaux, 2021)

SIA made an announcement on December 24th 2020 where she promised to help fund and produce a short film made by Communication First, which was to be screened before the main film MUSIC (Comunication First, 2021).

The collective gathered and worked with non-verbal autistic voices to view an early screening of the film, they then critiqued the film, all before starting production on their short. Though SIA and her team never got back to them after the screening, and two weeks before MUSIC, the collective went ahead funded and produced the short themselves without SIA or her teams help, and set the short film to release and be free to watch on YouTube the day of MUSICs release.

It could be argued that the 10 year period between Yoko Ono being commissioned in 2007 and the production of Sia’s film in 2017 would be enough time for the way that autism is portrayed in the media to be more true to the real life experiences of people on the autistic spectrum. While this is correct to an extent, the specifics of what this means in terms of representation of autism is still in need of improvement. To showcase this, a study done between January first, 2007 and December thirty-first 2016, in the news outlet the Washington Post an influential US newspaper that would have an impact on the general public due to its influence, and their mentions of “autism”, “autistic” and “aspergers” in the title of articles over that time period (Lewis, N. Akhtar, N 2020).

*“Although articles typically framed autism more positively over time, it is clear that the deficit view is alive and well. Increases in the use of neurodiversity terminology and inclusion of an autistic perspective were not statistically significant, and there was no significant change in the use of deficit terms, the labels mild/severe, high/low functioning, nor in talk of curing autism. Finally, though there was a significant decrease in articles portraying only clinicians or researchers as experts on autism, there were very few articles that portrayed autistic people as experts on their own condition. In the rest of the Discussion, we provide a more detailed discussion of the changes over time in how autism was portrayed, as well as some qualitative themes that emerged.”* (Lewis, N. Akhtar, N 2020).

They categorised and looked at 315 articles using four different methods to analyse the articles, Valence, Neurodiversity measures, Deficit measures and categorisation in the paper.

There were several positive points of improvement such as where mentions of strengths in autism, such as memory and pattern recognition, talk of accommodations in the workplace, and is less talk of catching autism after the Wakefield 1998 Vaccine study was redacted and over time the idea of “catching” autism lessened (Jonathon, D 2018).

 Autistics were still described as lacking something, and “symptoms” of autism and stigmatising in terms e.g. low and high functioning autism were still used.

Very few of the articles contained autistic perspective or framed autistics as experts themselves, whereas otherwise they referred to clinicians, researchers and families of autistic individuals being the experts, with many of the articles being on autistic children, not autistic adults.

*It should also be noted that many of the articles focused on autistic children rather than autistic adults, which is problematic because it contributes to the silencing of adult self-advocates by effectively ignoring their existence* (Lewis, N. Akhtar, N 2020).

**CONCLUSION**

In conclusion, the impact of the artist as a celebrity can be significantly damaging with their influence on the public’s view of marginalised groups. In this case, autism has both been used as a marketing tool and to make profit for organisations like Autism Speaks.

 SIA’s musical sequences in the film are an example of autism being used on a cosmetic level, which spreads myth and misinformation through her public influence.

Yoko Ono and her support in raising funds for Autism Speaks shows how little celebrities investigate the actual issues they back with their influential status.

Overall, celebrities like SIA and Yoko Ono have a great social responsibility to authentically represent autism through their celebrity status. If they worked with, and listened to, autistic voices in their endeavours concerning autism, we could have better representation overall in today’s media.

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