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Autism: The Musical

I have no idea if we're going to be able to pull it off. Autistic kids by nature are isolated. They're not supposed to be able to be spontaneous or imaginative; sounds can be too loud so how can you have group of kids singing. I want to have a musical; I want to have an all-out musical. There's all these myths about what a child with autism can do. I plan to shatter those myths. (Autism: The Musical, 2008)

Tricia Regan's new documentary film, "Autism: the Musical", begins with these words by Elaine Hall, a mother of a child with autism and the creator of "The Miracle Project". The Miracle Project is a collaborative musical theatre program that brings together children with autism and their siblings to stage a one-night only performance. The film features five of the many children involved in the project and their families. Each family has a unique story to tell, but all share a common theme of fighting for the inclusion and acceptance of their child with a disability.

First, there is Neal, Elaine Hall's son, who was adopted from Russia. Upon learning that Neal has autism, Hall became involved with alternate therapy rehabilitation. She recounts working with "theatre people" to immerse herself in her son's world and begin to draw him into her world. This process inspired her to start The Miracle Project. Parents at first are skeptical; however, Hall reassures them and the project gets underway:

I have no idea what's going to happen... I can promise you the first couple of weeks are going to be chaotic... but what I do know is they will be walking into an environment of people who will love them and accept them and be with them for who they are.

The other children profiled include Lexi, a fourteen-year old song bird, who can sing complex songs beautifully but is shown as being unable to carry a conversation; Henry, the dinosaur smitten child with Asperger's who is being excluded at school; Wyatt, who is unhappy being in a special education class and longs to be included in the mainstream, but is also dealing with bullying in his school; and finally Adam, the sweet, music loving eight-year old, who due to advocacy on the part of his mother, has been integrated into mainstream school.

This film was conceptualized when director Tricia Regan was approached by some parents who knew about the project and who wanted to bring greater public awareness to some of the issues surrounding autism. It's clear from the film that she wanted to tell a more encompassing story that includes not just the medical aspects of autism - often a predominant

theme in representation of disability in the media – but also the advocacy and coping strategies of families who have a child with a disability.

When reviewing and investigating disability in film it is important to realize that, on the whole, popular culture and mass media often ignore disability. When a character with a disability is included in a movie, TV show, or other form of popular culture the character is often underdeveloped. The character rarely faces the real and pressing issues affecting people with disabilities, issues such as inclusion, equal rights and employment. Disability is typically presented as an individualistic “medical” issue, leaving aside any social implications. More often than not, cultural representations of people with disabilities fit into familiar stereotypes – the distorted villain, the impoverished victim needing our pity, the “supercrip” with extraordinary abilities and powers or the fool who is constantly the butt of the joke, to name a few.

It is also important to remember that the images presented in media have a significant impact on the way we as a society view and approach disability rights and issues. Media portrayals can also serve as barometer for the views already held by society on a particular issue. As can be seen with the recent controversy over the use of the word “retard” in Ben Stiller’s movie “Tropic Thunder”, the desensitization of the public to certain harmful language and discourse can hurt the cause of activists petitioning for equality. By changing the way disability is conceptualized in pop culture, we have a means of influencing the way people think about disabilities.

So, what would a positive portrayal of people with disabilities look like in film? When presented through a “disability issues” lens, people with disabilities would be shown as equal to their able bodied peers. The film would reveal a clear and articulate understanding of the real issues and social barriers that affect people with disabilities. Significantly, characters would be represented by people with disabilities, not by a big-budget movie star “acting” as if they use a wheelchair or have a learning disability.

With the above in mind, how does *Autism: The Musical* measure up to this broad definition of a more positive mode of representation? I had the opportunity to present work on disability

and film at the recent annual Community Living Ontario conference and included *Autism: The Musical* as one of the films we examined. I felt that this film was a good example to show. It does include one of the more positive portrayals of people with disabilities in current film, but it also falls short in some areas, showing that even in the best intentioned efforts, there may still be pitfalls to the way we think about and conceptualize disability.

In many representations of disability, concern about disease and individual impairment are underlying the gloss of a more socially inclusive framework. *Autism: The Musical* is no different. The medicalization of disability is present from the very first frame. Statistics outlining the increase in the diagnosis of autism over the past 20 years present autism as a frightening epidemic that is running rampant and infecting our children. Several of the parents also speak from a medically minded perspective. Henry’s mother, Kristen, speaks about her own theory of causation, stating:

It’s so hard to say what causes autism because there are so many theories. I’m one of the people who believes it’s the kettle of beans. You throw in a bean, here’s the vaccinations, here’s the antibiotics, here’s the toxic environment, here’s the mercury in the fish mom ate while she was pregnant, and you throw enough beans in the kettle and its going to tip over.

Also of concern is the group’s name: *The Miracle Project*. This label suggests that the project aims to far exceed the ordinary accomplishments of people with disabilities. Anything that can be achieved by this group of children is viewed as a miracle because it is not something that is clinically and socially believed to be possible for individuals with autism. Needless to say, this assumption is offensive and regressive. For a project that has socially inclusive aims, a different title would have been welcome.

Throughout the film there is also a common thread of trying to “normalize” the children. The parents are constantly trying to move away from having their child viewed as “disabled”; instead the focus is to ensure the children behave in a way that is as “normal as possible” and socially appropriate. While the ultimate goal is inclusion and acceptance, this attempt to mask difference can be harmful in the long-run to an individual’s

identity as a person with a disability.

Despite the shortcomings outlined here, the tone and content of the film still emerge as positive. While there is discussion of the medical aspects of autism, the film also focuses on the children and their families, identifying social barriers from both perspectives.

A common theme among the parents is marital difficulties and, in some cases, separation and divorce. Elaine describes the demise of her first marriage four years previously and Adam's parents, Rosanne and Richard, talk about the infidelity that has rocked their marriage. Rosanne explains, "the month that Adam got diagnosed Richard embarked in an affair and this went on for sixteen months without my knowing... he definitely had the affair as a way to completely distance himself from it". In her portrayal of the parents, Regan doesn't judge who is right or wrong, but presents both sides of a complex relationship.

Lexi's parents, Hillary and Joe, are in the midst of a separation, in this case, fueled in part by Hillary's inability to accept Lexi's disability. As the project unfolds Hillary tries to find new ways to accept and advocate for her daughter. She is one of the most complex characters to watch; she has internally struggled with accepting Lexi as a person with a disability, but at the same time is trying to express her love, and advocate for her daughter's rights. In an intense scene, the parents meet while their kids rehearse and Hillary expresses her frustrations:

Why is my daughter in eighth grade and learning how to wash dishes? Because they don't value her. Because she's "autistic", and she's "stupid" and "she can't learn". So we're going to train her so that she can push a broom at McDonalds. I want the world to welcome her and they don't. And I can't make them, I can only work with who I've got. It's a value, and until these humans are valued, nobody's is going to find a cure, nobody's going to take the chemicals out of the vaccines, nobody's going to make the school system follow the law, nobody's going to make the doctor's follow the law, nobody's going to give us insurance, because they're not valued! ... I can try to enlighten, but I can't make them value her, I can't make them respect her and think she's got the same rights that they do.

This example demonstrates an internal conflict and frustration faced by many parents in the film, and as in reality, is not easily resolved.

The parent as an advocate is another shared theme among the families participating in the documentary. Adam's mother, Roseanne, is fiercely dedicated to the inclusion of her son, and in a highly charged scene she butts heads with Elaine over the way The Miracle Project's rehearsal runs. "My job is to do everything I can to keep [Adam] out of an institution... There's nothing he can't do, I just have to find a way to teach it to him." The legal (and financial) challenges some families face are also presented when Wyatt's parents visit a lawyer to explore their legal options for getting him into a mainstream school. These candid and honest interviews with the parents show not only the effect of social barriers on their children, but also on the family structure.

Barriers are also tackled from the point of view of the child. Wyatt talks about how the kids in the Miracle Project, including himself, have the tendency to "go into their own worlds". He expresses his frustration at not understanding why he and the others do this and the challenges that he has creating friendships. "I like being with somebody, because it makes me feel happy inside. When I'm with a friend that can be kind, that cannot be mean, not rude, not like a bully, just a friend."

Bullying and social exclusion are brought up over and over again by the children of The Miracle Project. One of the best features of the project is its participatory design; the content and storyline of the play are controlled and shaped by discussions the staff have with the kids. In one memorable scene the staff choose bullying as a "hot topic" to be discussed in the play. Here they took a topic that all of the children could understand and had experienced directly. Children could act out and discuss bullying together safely. As part of their explorations, the children tried out role reversal. Upon being asked what it felt like to be the bully for a change, Wyatt exclaims, "I felt great! Fabulous! Spectacular! It's fun being a bully!" and when asked what he would do now about the real bullies at school he replies "Mmm that's the mystery!" The reclamation of a harmful issue, is clearly an empowering tool. Overall the children in the film are not shown as one-dimensional, their complexity is thoughtfully revealed. The

documentary allows for each child's value to shine through without downplaying the social barriers and stigma they face.

Several clips touching on these themes were shown to the audience at the Community Living presentation. The audience was composed of workers in the disability field, parents and self-advocates. The audience's reaction to the film was quite positive, if not a bit quiet. During the Question and Answer period of the presentation, one individual asked if the parents and staff of the Miracle Project had been successful in "fixing" Neal through rehabilitation. This comment begs two questions: "How much power do the negative images presented in the media have over us, even as disability activists and advocates?" and, "What are we, ourselves, desensitized to as a result of media exposure and cultural assumptions based on a medical mode of thinking?"

At one point in the film Adam's support worker, Veatrice, says, "It really breaks my heart when I kind of realize, Wow, if he wasn't autistic, you can just imagine the possibilities." The very person who should be supporting and encouraging Adam is, here, expressing a view based entirely on social expectations and norms that are not inclusive. Once we begin to understand what our own personal biases are, we can start to change the way disability is presented in media and the perceptions that are an offshoot of this. When Elaine Hall states that she plans to "shatter the myths of autism" she has the right idea, but it is time that a child's successful participation in programs like The Miracle Project are no longer viewed as a miracle but as a normal and expected part of life for children with a disability.

Acknowledgements

"Autism: The Musical" is the winner of several film festival awards and has been nominated for five Emmy's in 2008. The film is now available on DVD through Docurama Films.

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