



Disability Inclusion Lab

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UCLA Autism Media Lab 2019 ***Inclusion is Hard. It's Worth It.***

Film Tool Kit: *SAINT YARED ANGELS*

INTRODUCTION

Imagine being locked inside a cage where no one could hear you, no matter how loud you screamed. That is the life of people with a form of autism that prevents their body from communicating through speech, even though their minds are sound and they have the same thoughts as you and I.

Now imagine a communication revolution that gave them a voice after years of being silent, and perceived as incapable of intelligence.

Now imagine these people make films about what it is like to live with autism, and the challenges they face to be included in society.

That is, in short, the Autism Media Lab, a ground-breaking documentary film production course at UCLA. From the Autism Media Lab comes a series of seven unique documentary shorts, created by non- or minimally speaking people with autism in close cooperation with UCLA students and faculty.

BACKGROUND

In 2019, the University of California at Los Angeles's Disability Inclusion Lab embarked on a cutting-edge course that endeavored to explore inclusion from in front of and behind the camera. The Autism Media Lab explored inclusion for people with autism who are non-speaking, minimally-speaking or unreliably-speaking through a unique fusion of disability studies and documentary film. This course allowed students to learn directly from non- and minimally-speaking individuals with autism called Community Teachers. This unique learning environment ensured that discovery came from immersion in both scholarship and the lived experiences of individuals facing barriers to inclusion.

The lab formed six film crews comprised of undergraduate students partnered with the Community Teachers. The crews were guided by faculty from both the UCLA Disability Studies (Judy Mark) and Film Departments (Sjoerd Oostrik) as well as a graduate student teaching assistant from the Department of World Arts and Cultures/Dance (Jingqiu Guan). The film crews collaboratively created six short documentary films, each exploring inclusion in various community settings with a goal of identifying pathways to inclusion. The films explore exclusion of people with autism in education, employment, friendship, public safety, health care, and religious communities.

In addition, faculty and filmmakers Oostrik and Guan made a seventh film that explored the making of the Autism Media Lab and the challenges faced to ensure inclusion behind the camera as well. The final “making of” film features the students and community teachers as they learn together in class, behind the scenes as the films are made, and as some of them make a trip to the United Nations to present the class at World Autism Awareness Day.

We hope that the documentaries will be used as conversation starters on the subject of inclusion.

DISCUSSION FORMATS

The idea of this toolkit is to give you the means to set up a focused conversation among your audience and within your community; a discussion that focuses on a few pre-determined topics with the goal of cultivating an in-depth and generative dialogue on these topics that could lead to action.

Two options for the format of the discussions following the screening include:

1. A Q&A format between a conversation moderator and the audience, using provided questions below.
2. A panel discussion with real-life experts—people with autism. If no self-advocates with autism are present at your screening, or no one is willing to take part in a panel, you can also ask family-members and friends, professional caretakers, or experts to take part in the panel. The panel could also answer some of the questions provided in this toolkit.

You can also choose to mix both formats depending on your targeted audience and the results you hope to achieve through the screening.

We recommend using the questions of this tool-kit to steer the conversation as much as possible towards the more difficult questions and points of action. The organizer can choose to share these questions prior to the film screening and guide the audience to keep these questions in mind while watching the films.

We also include ideas for action called, “Try Harder.” The actions are suggestions from the filmmakers on what audience members can do to encourage inclusion for people with autism. Some actions may be more appropriate for certain audiences. These ideas are in no way exhaustive and we encourage the organizations sponsoring the film screenings to develop additional ideas for action.

TIPS FOR FACILITATING AND MANAGING DISCUSSION

1. Inclusion of people with autism in your post-screening discussion

Because inclusion is the theme of the films, we always recommend giving autistic self-advocates the possibility to take key roles in the post-screening conversation, particularly those who type to communicate, such as typing on a letter board or an iPad. The self-advocates should be given the option to take part in the panel or to present. Because it can take self-advocates who type to communicate more time to answer questions, it is always a good idea to give them the questions several days before the actual screening so they can prepare their answers.

If people with autism who use alternative methods to communicate are going to answer questions live at your post-screening discussion, they will likely need additional time. It is important to ask the autistic person before the screening how they would like to answer questions live. Here are some possible options:

- After the question is posed, the audience can wait while the person with autism is typing.
- After the question is posed, the discussion moderator can have a speaking person on the panel answer the question while the person with autism types out their answer.
- Right after the films are shown, the audience members can write down their questions, which can be provided to the panelists. As soon as a panelist has typed their answer, the moderator could read the question and the panelist could use their device or support staff to read their answer.

2. Words Matter

When facilitating a discussion about the inclusion of people with non-speaking or minimally speaking autism, it is important to ensure that the conversation is respectful and recognizes the value that they bring to our communities. You want to correct any negative stereotypes that may surface in the discussion, such as those that question an individual's intelligence or ability to communicate.

3. "Person with Autism" versus "Autistic Person"

There is a debate within the autism community about whether you use person-first language ("person with autism") or identity-first language ("autistic person" or "an autistic"). Many in the disability rights community believe that person-first language is the most respectful because it implies that the individual is a person first and their diagnosis is not all that they are. But many self-advocates with autism argue that being autistic is as much a part of their identity as race, gender, religion, or sexual orientation. If you are including autistic self-advocates on a discussion panel, you should ask them how they would like to be identified. In our films, you will hear both person-first and identity-first language and, during our course, we would use both terms depending upon how the individual wanted to be identified.

4. Inclusion versus Segregation

The theme of the films is "Inclusion is hard. Try harder." You may encounter audience members who have tried inclusion and find that it didn't work. They may advocate for special programs, classrooms, and housing communities for people with autism. During the discussion, it is important to probe why inclusion hasn't worked and what could have been improved. Ask, "Were there enough supports in place? Was everyone at the school committed to inclusion? What other barriers existed?" There are many examples of inclusion working successfully, but behind that success almost certainly existed people who fought very hard for inclusion against significant challenges. You could ask the audience for some inclusion success stories or ideas.

STRUCTURE OF THE GUIDE for SAINT YARED ANGELS

For each film, we included discussion questions based on specific themes and scenes we identified. The call-to-action section encourages the audience to identify one specific, relevant, and executable action. Finally, we also provided a list of suggested readings related to the topic each film addresses. These readings offer helpful contextual information for each film.

***SAINT YARED ANGELS* Film Description:**

Saint Yared Angels tells the beautiful story of how families with children with autism fought for several years to include their children in classes and services at the Virgin Mary Ethiopian Orthodox Tewahedo Church in South Los Angeles. The clergy wanted to help but didn't know how. So the community came together and figured out a way to meaningfully include everyone in their congregation, regardless of ability.

Discussion Questions

A. Not Feeling Welcomed

In the beginning of the film, parents express how they felt when bringing their children with autism into the church. Aida said, “There are some members they didn’t understand. They would whisper... The challenge was how we felt. We were uncomfortable because we thought we were making other people uncomfortable. We would try to control him. Migrates added that “Sometimes I feel like I’m not welcomed.”

1. Why would these parents feel this way? Were they justified or were they being too sensitive?
2. What do you think the obligation is for religious communities to include people with autism or other disabilities?

B. The Importance of Being Included in a Religious Community

Emmanuel and his father Mulugeta speak about why it is important for them to be part of their Ethiopian Church. Mulugeta explains, “Even though they don’t say it, I know they have a really good bond and friendship and it gives us a really good feeling.” And the High Priest talks about the importance of inclusion to his church, “When we listen to the parents, we are learning a lot. Not only about children with special needs, but also about humanity, in general.”

1. Why is it important for people with autism and other disabilities to be included in religious communities?
2. What benefits does inclusion bring to a religious community?
3. Do you belong to a religious community? If yes, do you think that people with autism would benefit in the same ways you do? Would they benefit differently?

C. Not Knowing How

In the film, the high priest struggles to figure out how to include people with autism in his congregation. He says, “Sometimes we try to do something good but we create another problem.” Mulugeta explains, “Awareness is really important. We are fearing that we are not accepted by the church but we found out that was not true... People wanted to help us but they don’t know how.” But the families have found a way in through perseverance and faith.

1. What are the challenges that religious communities face in including people with autism and other disabilities?
2. What ideas would you have to ensure inclusion in religious services? In religious education programs? In religious rituals and holidays?
3. What accommodations need to be in place to include people with autism who might not communicate with speech or might make noise during the service?

Call to Action

What can you and your community do to make sure people with autism are more included in their religious communities? Try to come up with at least one action you can take in the immediate future.

Suggested Readings

Briggs, D. (2018, July 20). Study: US Churches Exclude Children with Autism, ADD/ADHD. *Christianity Today*. Retrieved from <https://www.christianitytoday.com/news/2018/july/study-us-churches-exclude-children-with-autism-addadhd.html>

Walsh, M.B., et al. (2008). *Autism and faith: A journey into community*. Elizabeth Boggs Center on Developmental Disabilities and Robert Wood Johnson Medical School. Retrieved from <https://rwjms.rutgers.edu/boggscenter/products/documents/AutismandFaith-English2011.pdf>

Kaplan-Mayer, G. (2018, September 4). 10 ways to make your synagogue more accessible to people with disabilities. *Forward*. Retrieved from <https://forward.com/life/faith/407764/10-easy-ways-to-make-your-synagogue-more-accessible-to-people-with/>