



Disability Inclusion Lab

Powered by UCLA Disability Studies

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

Film Tool Kit: *ABOVE THE DEPTHS*

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 ABOVE THE DEPTHS

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.

ABOVE THE DEPTHS Film Description:

For years Daniel Rosien, 18, had the feeling he was treated like an animal. Even though he types independently to communicate, his school district would not let him be included in typical classes. They thought he had a very low IQ, and only gave him the simplest kindergarten level assignments for years on end.

But Dan has a knack for math and physics and wants to work for NASA. Now together with his parents and his communication partner, he gives up the fight to be included in general education in high school and turns to homeschooling. But he pursues his dream to go to college and someday be a physicist.

Discussion Questions

A. Low expectations

In the film, Dan talks about his education when he was a child. He says that his “teachers talked to us like we were pets,” and “it was a joke.”

1. Why do you think he felt that way?
2. Have you or someone you know had that experience?
3. What do you think contributes to low expectations of people with autism?

B. Ability to communicate

Dan also says: “Everyone in the district assumed I was dumb because I can’t talk.” He also said that gaining the ability to communicate through typing “changed my life.”

1. Why is the ability to communicate so important for people who are non-speaking?
2. What steps can be taken to ensure that people with autism are given the ability to communicate?
3. What are the barriers keeping people with autism from gaining this ability to communicate?

C. Inclusion in academics and higher education

Dan’s communication partner, Molly Rearick, says in the film, “You have two choices: one of which is to include them and to teach them geometry and history and all of the things you would teach anybody; the other choice is to not do that. The least dangerous assumption is to include them because even if they can’t show you what they know, maybe they’re learning something, maybe not. But if you don’t include them, then you know for sure they’re not learning.”

1. Do you agree with this statement?
2. How do we make inclusion work?
3. What are the roadblocks being put in the way of people with non-speaking autism getting included in academics and reaching for higher education?
4. What kind of accommodations would someone like Dan need to get fully included in academics?

D. Presuming competence

Presuming competence is an important theme in the film. Molly says hopefully, “We talk about presuming competence and that speech doesn’t equal intelligence.” She also says, “I see Dan having a life where it doesn’t matter if he types instead of talking.” Dan’s father, Chris, goes further and states, “When you presume competence, you just naturally change the way you relate to them.”

1. What does “presuming competence” mean to you?
2. What would it look like in a classroom?
3. How can we help teachers, aides, other professionals, and parents to presume competence?

Call to Action

What can you and your community do to make sure people with autism get the education they deserve? Try to come up with at least one action you can take in the immediate future.

Suggested Readings

Ito, J. (2018, September 6, 2018). The educational tyranny of the neurotypicals. *Wired*. Retrieved from <https://www.wired.com/story/tyranny-neurotypicals-unschooling-education/>

Sequenzia, A. (2013, September 26). More problems with functioning labels [Web log post]. Retrieved from <http://ollibean.com/problems-functioning-labels/>

Kedar, I. (2016, March 31). Tips for Teachers Integrating a Nonverbal Student with Autism into their Class [Web log post]. Retrieved from <http://idoinautismland.com/?p=438>

Prizant, B. (2015). We have autism all wrong: The radical new approach we need to understand and treat it. In B. Prizant & T. Fields-Meyer, *Uniquely human: A different way of seeing autism*. Retrieved from http://www.salon.com/2015/08/16/we_have_autism_all_wrong_the_radical_new_approach_we_need_to_understand_and_treat_it/