



# Disability Inclusion Lab

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

### Film Tool Kit: *WHAT BILLY COULDN'T SAY*

#### 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 *WHAT BILLY COULDN'T SAY*

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.

### ***WHAT BILLY COULDN'T SAY* Film Description:**

This chronicle of a death foretold, shares the tragic story of Billy, a severely autistic young man who was let down by every system designed to support him. Coming from a family that couldn't pay for private insurance, Billy never received the care he needed: schools and regional centers couldn't handle him, behavioral therapy came too late, and hospitals flat out refused him at the door. The cheapest and quickest option left on the table was the use of heavy psychotropic medications. At the age of 18, Billy died of Neuroleptic Malignant Syndrome, a cardiac arrest caused by overmedication. *what Billy couldn't say* explores the connection

between poverty and poor health care and how it can lead to a catastrophic ending, particularly when the patient is disabled and non-speaking.

## **Discussion Questions**

### **A. Overmedication**

Psychiatrist Derek A. Ott treats a lot of people with developmental disabilities including people with autism. He says in the beginning of the film that he has seen many individuals in his practice that are on four, six, or sometimes eight different types of psychiatric medications, and that he often works to reduce to that number. In Billy's toxicology report it was stated that five different types of drugs were found in his blood. His cause of death was determined to be Neuroleptic Malignant Syndrome, a life threatening reaction that occurs in response to antipsychotic medications.

1. Do you think that medical professionals are too quick with prescribing psychiatric medications, particularly for people with autism?
2. Why do you think this happens?
3. What can be done to change this?

### **B. Refusal of patients**

Billy's mother Lucy Lopez had trouble finding neurologists and psychiatrists who were willing to treat Billy. Dr. Ott recognizes that it happens that patients with severe behavioral issues who are on a complicated regimen of medication are sometimes refused, because of financial motivation and of trouble with placement afterwards.

1. Have you experienced or do you know of others who have had a hard time finding a doctor to treat a person with non-speaking autism?
2. Why do you think this happens?
3. What can be done to change this?

### **C. Health insurance**

Billy's mother, Lucy Lopez, shares that Billy lost his private insurance and had to rely on Medi-Cal, the public Medicaid health option in California. According to a study of Rutgers and Columbia Universities, children and adolescents on Medicaid were five times more likely as those with private insurance to be prescribed antipsychotic medications.

1. Why would a doctor treat a person on public insurance differently than a person with private insurance?
2. Did you or someone you know experience different types of treatment if they were under different kinds of insurance policies? What kind of differences?
3. What do you think is the role that money plays in quality healthcare?

## **Call to Action**

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

### **Suggested Readings**

Crane, S. (2013). The transition to adulthood for youth with ID/DD: A review of research, policy, and next steps. Retrieved from the Autistic Self Advocacy Network website: [https://autisticadvocacy.org/wp-content/uploads/2013/12/HealthCareTransition\\_ASAN\\_PolicyBrief\\_r2.pdf](https://autisticadvocacy.org/wp-content/uploads/2013/12/HealthCareTransition_ASAN_PolicyBrief_r2.pdf)

Opar, A. (2018). The healthcare system is failing autistic adults. Spectrum.  
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<https://www.spectrumnews.org/features/deep-dive/healthcare-system-failing-autistic-adults/>

AASPIRE. (2014). Health care toolkit for health care providers. Retrieved from

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