

AIAW Discussion Guide Outline & Web Outline

(the discussion guide will be accessed through www.cnn.com which will link to www.autismisaworld.com .The information on holding a screening, will only be on the program site)

Synopsis

She is her own worst nightmare. When you meet Sue, she does not make eye contact. She does not offer to shake your hand. She may fixate on the buttons of your shirt, but cannot say your name. Sue Rubin has autism, a complicated disorder that causes her to act in many strange ways. For researchers, doctors, and psychologists, autism is mysterious and complex, its causes and cures still unknown. But this is not a film about experts or theories. In *Autism is a World*, Sue takes the audience on an extraordinary journey inside autism to explain what she feels and does. How she relates to others. Why she clutches spoons or finds comfort in falling water. What it has been like to go to college and run her own life. This is a view of autism as it has rarely been seen--from the inside out.

As a child, Sue did not give her parents much hope. She hit herself. Pulled hair. Bit her own arms and hands. She could not speak. Her mother Rita and her father Bob say they did everything to try to help. At age four, they took Sue to UCLA to explore the possibility that she might have autistic tendencies. The answer was clear and quick: forget “tendencies,” Sue is severely autistic. As Sue interviews eminent Harvard researcher Margaret Bauman, we learn it is a disorder still barely understood.

Until she was 13, most believed Sue to be retarded. Repeated tests put her IQ at 29—“the level of a 2 year old.” Rita says that her hopes for Sue, then, were modest—to keep her out of an institution, to educate her in special classes, to someday help her get a job “cleaning tables off or something like that that retarded people do.” But then, just before she was 13, Sue’s psychologist, Jackie, introduced her to “facilitated communication.” Jackie and Rita worked with Sue tirelessly and, slowly; the little girl trapped inside her silent, strange behavior began to communicate and to emerge into the world an aware, intelligent young woman. When Sue was retested months later, the results were stunning—a 133 IQ. Sue entered regular high school classes.

Today, Sue is a junior at Whittier College with a history major. We see her in class, hear how hard it is to control her behaviors during the lecture, and find that she loves learning. And, we meet Aishling, a friend since high school, a fellow student and, for the last 7 years, part of Sue’s complicated network of support staff who make her life possible.

Sue takes the audience through her daily life—through fun excursions with staffer Danny to bet the horses at Santa Anita, trips to the store to shop for groceries, and struggles to do what, for most, would be mundane tasks like making a salad or tying her shoes. We learn that Sue clutches at plastic spoons because they bring her comfort. We see her play for long stretches at the sink in a trickling flow of water during which, she says, the autistic side of her brain takes over. It is a startling juxtaposition—the clear, intelligent, articulate words of a woman who is behaving in the world in exceptionally strange ways.

Sue has become a tireless disability rights advocate. We watch her write a speech for a conference on autism. During the long process of writing, Sue’s support staffer Lisanne keeps her focused. Here, Sue demonstrates her wit, intelligence, and compassion. She starts by telling her audience, “If you think living with autism is difficult, try getting into college” and ends, in a tender moment, with a very personal offer to help others with autism who hope to follow in her footsteps.

As the film moves to its conclusion, it comes to a wrenching emotional climax. After years, it is time for Aishling and Lisanne to leave Sue’s staff and pursue other interests. In meetings with psychologist

Jackie, with her mother, with staff coordinator Janine and with Aishling and Lisanne, it is clear that Sue is struggling and that the change is painful.

Sue shares her final thoughts as the film concludes. Her words are simple: “The last thing I want to clarify is that no matter how much social interaction one has, one will never be free of autism. The tendencies to be and act in certain ways may subside but I will always be autistic.”

DISCUSSION GUIDE

For researchers, doctors, and psychologists, autism is complex - its causes and cures still being unraveled - but this is not a film about experts or theories. In *Autism is a World*, Sue Rubin takes the audience on an extraordinary journey inside autism to explain what she feels and does. This is a view of autism as it has rarely been seen--from the inside out.

To assist you in viewing this film, we have developed this discussion guide that will give you background on Sue Rubin, autism and additional resources. [Tips on Holding a Screening](#) will provide you with a step-by-step guide to showing this film with a group. We include guiding questions to encourage discussion. We hope you find this useful.

Synopsis of *Autism is a World*

What is Autism?

What is Facilitated Communication?

Tips on Holding a Screening

For More Information

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What is Autism?

"Autism is a world so difficult to explain to someone who is not autistic, someone who can easily turn off the peculiar movements and actions that take over our bodies." – Sue Rubin

Autism is the common term for a range of disabilities medically classified as Pervasive Developmental Disorders (PDD). Autism/PDD is characterized by qualitative differences in the development of cognitive, language, social or motor skills, and these are usually apparent before age three. Research evidence suggests that autism may result from an underlying difficulty with expressive movement and its regulation, severely challenging the individual to keep body movements, including sensory responses, in control. These sensorimotor problems can make it difficult to respond consistently and productively to other individuals and to the environment.

What is the prevalence of Autism Spectrum Disorders (ASDs)?

Data from several studies that used the current criteria for diagnosing autism and autism spectrum disorders (ASD), such as Asperger's disorder and pervasive developmental disabilities (PDD-NOS), found prevalence rates for ASDs between 2 and 6 per 1,000 individuals. Therefore, it can be summarized that between 1 in 500 (2/1,000) to 1 in 166 children (6/1,000) have an ASD. (Center for Disease Control, 2004)

Autism/PDD is four times more common among males than females. It is found throughout the world in families of all racial, ethnic and social backgrounds. While autism was once erroneously believed to arise from stresses in a child's psychological environment, modern medical evidence suggests that irregularities in the development of the brain and central nervous system give rise to the syndrome of autism. Causes of this development are diverse and may include chemical exposure, viral and genetic factors.

Autism/PDD is not an illness or a "thing" a person "has." It is a collection of responses which must be viewed in context, and observation is always more productive than labeling. Across the wide spectrum of the autism/PDD syndrome, individual variations on several key features can be recognized. Reciprocal social interactions, both verbal and nonverbal, are unusual in quality and generally difficult to synchronize and to carry out. Impairments of the central nervous system typically result in over-reactions, under-reactions, or inconsistent responses to various sensory stimuli. Because sensory input is difficult to organize and control, the individual's activities and interests may appear restricted in their nature and repertoire, frequently involving significant repetition and a need for predictability rather than change. It is important to view the behavior of people with autism/PDD as meaningful adaptations and to take a positive, respectful approach to them, forgoing the common tendency to judge their competence and capacity on the basis of their sensorimotor challenges. (Source: Autism National Committee www.autcom.org/default/htm).

In addition, please refer to the list of autobiographical accounts of autism found at the end of this guide. These books provide a wealth of information on the first hand experience of autism, including explanations of behavior that often differ from clinical assumptions about the same behavior.

What is Facilitated Communication?

When she was 13 years old Sue Rubin began using a form of augmentative and alternative communication (AAC) called facilitated communication (FC). Facilitated communication is a way for people who cannot speak or who have limited speech to communicate by typing on a keyboard or pointing at letters, images, or other symbols to represent their messages. Through daily practice and careful support, Sue emerged as an effective communicator. Several years ago she began to type independently. Today, Sue types without physical support on a small keyboard.

Facilitated communication has been used as a means to communicate for individuals with severe disabilities, including persons with labels of mental retardation, autism, Down syndrome and other developmental disabilities. To learn more, go to:

- Facilitated Communication Institute, Syracuse University- <http://soeweb.syr.edu/thefci/>
- TASH Resolution on Facilitated Communication- <http://www.tash.org/resolutions/res02faccom.htm>
- Breaking The Barriers- <http://www.breaking-the-barriers.org/>

Tips on Holding a Screening

The first thing you should do is preview the video on your own. That way you will be familiar with the program and have an idea of which parts of the video will be particularly interesting as points of discussion for your group.

The video should be shown where everyone will feel comfortable discussing disability, their thoughts on autism, and how what they see in the video relates to their own lives.

Discussions can be facilitated by: students, parents and family members, special education & regular education teachers, individuals with an interest in autism, healthcare professionals, school administrators, or members of service and advocacy organizations.

Discussion Tips for Screening Facilitators:

- Plan each step of the meeting ahead of time.
- Begin with an ice-breaker – have everyone introduce themselves.
- Remind the group how to have a good discussion.
 - Everyone’s comments are important.
 - Please don’t use strong language or judge anyone else’s ideas.
 - Try to speak one at a time and use active listening skills.
- Remember that not everyone will agree – each person comes to the group with unique experiences.
- Use the pre-video questions to focus the attention of your audience.
- Remember that your role is to get everyone engaged in the conversation – try not to dominate the discussion & try not to lecture.
- Keep your attitude positive and keep the conversation going.
- Stay on schedule – and wrap up the meeting on time.

Beginning the Screening:

Before starting the video, tell to the people in the meeting what the video is about and introduce the topics of the conversation you hope to discuss after you watch the show.

Pre-screening Questions

The following are some questions you can ask people to consider while they watch the video. Tell them that these questions along with others will also be discussed *after* the video. Write the questions on a chalkboard or on a poster-board before the workshop and keep them up while you watch the video. You can also add your own questions, but remember not to have too many. Pick the questions that are best for your audience.

- What do you know about autism? What “image” do you have of someone with autism?
- What sorts of educational environments can best support students with autism?
- What are your expectations for how someone with autism will communicate?
- What kind of life do you envision or expect for people with autism?
- Will social relationships and friendships be different for people with autism? How does how you communicate affect your relationships?

Post-screening Questions

To maintain the focus on Sue and her story, we chose to use quotes from the film as a starting point for each question. While there is a lot to learn about autism by listening to and understanding the details of Sue's life and words, we must not make the mistake of assuming that Sue's experiences are the same for all others with autism labels. While some people with autism may experience similar issues, individual experiences of autism are just that.

- *“This is not my voice, but these are my words.”*
 - How did you react to Sue's words being read by someone else? How did you make sense of the difference between Sue's vocal communication and her typed communication?

- Sue Rubin *“I knowingly contribute to my looking retarded by carrying around a plastic spoon, but spoons are my comfort. I cannot explain how or why I need them. I just do.”*
 - What does it mean to look “retarded”?
 - How can you reinterpret Sue's need to hold spoons without making assumptions about her intelligence?
 - When you meet or interact with a person or a student who has a disability, how do you think your own stereotypes and assumptions affect how the person or the student is understood and perceived?

- Rita Rubin, Sue's mother: *“We knew that she would be retarded and we knew we didn't want her in an institution and we knew that she would be educated in special day classes with other people with severe handicaps and we knew that if she got a job when she was an adult it would be something like cleaning tables off or something like that that retarded people do.”*
 - Why were these assumptions so strong? Where do you think these assumptions come from?
 - Is “mental retardation” a helpful category? Is it respectful? What are the potential ramifications of such a label?

- Sue Rubin: *“I certainly understand why I was assumed to be retarded. All of my very awkward movements and all my nonsense sounds made me appear retarded. Perhaps I was. Voices floated over me. I heard sounds but not words. It wasn't until I had a communication system that I was able to make sense out of the sounds...As I began to type my mind began to wake up.”*
 - How did/do Sue's “awkward movements” impact people's evaluations of her intelligence? How do we tend to judge someone's intellectual ability by his or her appearance?
 - What was the effect on Sue and on those around her when she found a means to communicate?
 - Discuss various ways to provide a means of communication for people who have no or limited speech.

- Sue Rubin *“I love going to the race track because it is a place where I can blend in with the crowd and appear normal. Everyone is looking at the horses and not at me.”*
 - What was your first reaction to “meeting” Sue on screen? How did your assumptions change during the course of the film?

- What exactly do we mean by “normal”? What are the consequences of perpetuating the concept of normalcy?
- Sue Rubin *“When I watch water I am zoning out and letting the autistic part of my brain take over. My mind goes blank and I stop thinking.”*
 - Why might this be helpful (or necessary) for Sue?
 - What routines do you have that allow you to relax, regroup, or shut down at times?

EDUCATION

- Sue Rubin *“Autism is a constant struggle. It takes every ounce of energy I have to sit somewhat quietly during a two-hour lecture. I love learning yet being looked upon as feebleminded is something I have been forced to endure my entire life.”*
 - Describe Sue’s ongoing struggles as a college student.
 - What made it possible for Sue to become an honor roll college student? What supports and resources can she draw on to make participation possible?
 - If you were Sue’s teacher, what would you do to create an inclusive classroom where her struggles and needs are appreciated and accommodated, and where she is able to fully participate?

RELATIONSHIPS

- Sue Rubin *“Ashling and I have a dear friendship that has spanned twelve great years and many more to come. She is a true friend and both loves and antagonizes me like the sister I never had.”*
 - Much of the literature about autism contends that people with autism do not desire or simply cannot develop friendships. In light of such prevalent beliefs about autism, how did you make sense of both Sue’s desire and ability to enjoy friendships?
- Sue Rubin *“Autism is not a social way of life.”*
 - Support Sue’s statement with examples from the film.
 - On the other hand, how was Sue supported to interact with others and develop social relationships and friendships?

COMMUNICATION

- Sue Rubin *“Really hate it because nonverbal autistic people are not given an opportunity to show their intelligence.”*
 - What is the role of “context” in interpreting people with movement differences and alternative communication methods?
 - How do you think you would act and feel if you didn’t have the means and the opportunities to communicate or to show that you understand?
 - How can you support people with autism to show all that they do know?
- Sue Rubin *“As independent as I may become, the sad fact is that I will always need others to communicate, and emotions are most difficult to talk about.”*
 - Can someone be “dependent” on others’ assistance and still be “independent” at the same time? Is anyone truly independent? How do you make sense of the need for support staff and Sue’s own competence?

- How does a shift of focus from *independence* to *interdependence* help to resolve this dilemma?
- Why do you think Sue says it is a “sad fact?”

FUTURE

- Sue Rubin “*The last thing I want to clarify is that no matter how much social interaction one has, one will never be free of autism. The tendencies to be and act in certain ways may subside, but I will always be autistic.*”
 - Why does Sue end the film with this statement?
 - Given the various successes, achievements, and elements of fun that were a part of Sue’s life in this film, this last statement makes her story complex. How do you think this “complexity” might help us better understand Sue as a person?
 - Does her voice carry a hopeful or a defeated tone?

For More Information

Autism Online Resources

Advocacy/public education

- Autism National Committee (Autcom)- <http://www.autcom.org/default.htm>
- Autism Network International (ANI)- <http://ani.autistics.org>
- Autistics.Org- <http://www.autistics.org/>
- Autism Society of America (ASA)- <http://www.autism-society.org/>

Governmental sources on autism

- National Institute of Mental Health (NIMH)- <http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>
- National Institute on Child Health & Human Development (NICHD)- <http://www.nichd.nih.gov/autism/>
- National Institute on Deafness and other Communication Disorders (NIDCD)- <http://www.nidcd.nih.gov/health/voice/autism.asp>

General autism information/research organizations

- Autism Society of America- <http://www.autism-society.org/site/PageServer>
- Cure Autism Now (CAN)- <http://www.cureautismnow.org/>
- National Alliance for Autism Research (NAAR)- <http://www.naar.org/>

School and Community Inclusion Online Resources

- Association on Higher Education and Disability (AHEAD)- <http://www.ahead.org/>
- American Association of People with Disabilities (AAPD)- <http://www.aapd.com/>
- Center on Human Policy, Syracuse University- <http://thechp.syr.edu/>
- Disability Studies for Teachers - <http://www.disabilitystudiesforteachers.org/index.php>
- PEAK Parent Center- <http://www.peakparent.org/index.asp>
- TASH- <http://www.tash.org>
- Transition Planning <http://www.myfuturemyplan.com>

Other Suggested Resources

Books

- Biklen, D. (with R. Attfield, L. Bissonnette, L. Blackman, J. Burke, A. Frugone, T.R. Mukhopadhyay, and S. Rubin) (2005). *Autism and the myth of the person alone*. New York: NYU Press.
- Bluestone, J. (2004). *The fabric of autism: Weaving the threads into a cogent theory*.
- Donnellan, A. & Leary, M. (1995). *Movement differences and diversity in autism/mental retardation: Appreciating and accommodating people with communication and behavior challenges*. Madison, WI: DRI Press.
- Gillingham, G. (2000). *Autism: A new understanding*. Edmonton, Alberta, Canada: Tacit Publishing Inc.
- Kluth, P. (2003). *"You're going to love this kid!": Teaching students with autism in the inclusive classroom*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Mukhopadhyay, T. R. (2000). *Beyond the silence: My life, the world and autism*. London: National Autistic Society.
- Prince-Hughes, D. (2004). *Songs of the gorilla nation: My journey through autism*. New York: Harmony Books.
- Shore, S. (2001). *Beyond the wall: Personal experiences with autism and Asperger syndrome*. Shawnee Mission, KS: Autism Asperger Publishing.
- Villa, R. A. & Thousand, J. S. (Eds). (1995). *Creating an inclusive school*. Alexandria, VA: Association for Supervision and Curriculum Development.
- Williams, D. (2003). *Exposure anxiety: The invisible cage*. London: Jessica Kingsley Publishers.

Find more titles at:

The ANC Bookstore- <http://www.autcom.org/bookstore.html>

Jessica Kingsley Publishers- <http://www.jkp.com/catalogue/index.php?cat=autism>

Paul H. Brookes Publishing Company- <http://www.pbrookes.com>

Articles

- Broderick, A. & Kasa-Hendrickson, C. (2001). "Say just one word at first": The emergence of reliable speech in a student labeled with autism. *Journal of the Association for Persons with Severe Handicaps*, 26, 13-24.
- Mirenda, P. (2003). "He's not really a reader...": Perspectives on supporting literacy development in individuals with autism. *Topics in Language Disorders*, 23, 4, 271-282.

Rubin, S. (1997). A recipe for success. *Facilitated Communication Digest*, 6, 3-5.

Rubin, S., Biklen, D., Hendrickson, C., Kluth, P., Cardinal, D.N., & Broderick, A. (2001). Independence, participation, and the meaning of intellectual ability. *Disability & Society*, 16, 415-429.

More Information on *Autism is a World*:

<http://www.autismisaworld.com>

Special thanks to the Nancy Lurie Marks Family Foundation.

To Order:

Home Video

To order copies of "Autism is a World" for viewing in your home visit:

Amazon.com

<http://www.amazon.com>

Search for "Autism is a World"

Group Screenings - Public Performance Free Admission

To order copies of "Autism is a World" for viewing outside your home in a group setting with no admission charged, classroom and educational settings, community screenings as well as institutional events you *must* purchase the public performance rights. To purchase copies of "Autism is a World" with public performance rights please contact the following distributors:

National Professional Resources

Syracuse, NY 13220-2038

<http://www.nprinc.com>

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Tel: 1 (914) 937-8879 (other areas)

Fax: (914) 937-9327

service@nprinc.com

Mailing Address:

National Professional Resources

25 South Regent St.

Port Chester, NY 10573

Program Development Associates

<http://www.pdassoc.com>

Tel. 1 (800) 543-2119

Tel. (315) 452-0643

Fax. (315) 452-0710

info@pdassoc.com

Mailing Address:

Program Development Associates

P.O. Box 2038

Public Performance Paid Admission

To order copies of “Autism is a World” for screenings with paid admission contact:

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Tel. (202) 537-0818

Fax. (202) 537-0828

office@stateart.com

<http://www.autismisaworld.com>

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