

ORCHESTRATINGchange

DISCUSSION GUIDE



ORCHESTRATINGchange

a film about

THE WORLD'S
ONLY ORCHESTRA
for people living
with mental illness



a film by

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1. FILMMAKERS' STATEMENT

When we learned about Me2/Orchestra we knew we had to make a documentary film about this extraordinary orchestra founded by Music Director, Ronald Braunstein, and Executive Director, Caroline Whiddon. As Caroline says in the film, “Who knew an orchestra could be such a vehicle for social change?” The orchestra’s mission is to combat the stigmatization of people living with mental illness, still an issue clouded by fear and outright ignorance. They do so by combining musicians living with mental illness and those who support them in an atmosphere of acceptance and compassion.

For many people, their image of mental illness is influenced by the portrayals we see in the media when inexplicable acts of violence and tragedy occur. Statistics prove that people living with mental illness are far more likely to be the victims of violent crime rather than the perpetrators. But that fact rarely makes headlines. Although nearly all of us have a family member, friend or colleague living with mental illness, people who need help often do not seek it for fear of being exposed to the societal stigma and shaming that too often goes along with a mental health diagnosis.

It would have been easier to sugarcoat the story and make a film about a unique orchestra working toward a major concert. But we wanted to leave viewers with a deeper and more nuanced view of what it really means to live with a mental illness. Several of the Me2/ musicians generously shared their lives with us, good times and bad, as we filmed over two years. We are extremely grateful to these musicians for their incredibly honest and insightful awareness of what it means to live with a mental illness on a daily basis—and their humor. We hope they will inspire others living with mental illness to, as flutist Sandy says to “be loud” about living with mental illness, come out of the shadows and end one of society’s last taboos.

Our hope is that *Orchestrating Change* will encourage conversation about mental illness and help change the deeply entrenched negative images we see in the media. We want to encourage viewers to challenge their own perceptions, misconceptions and fears about mental illness. And to enjoy the beautiful music produced by the Me2/Orchestras.

Margie Friedman & Barbara Multer-Wellin

2. ABOUT THE FILM

Me2/Orchestra has created a model for society where people with and without mental illness can work together in an environment where acceptance is the norm and supporting each other is a priority. While hearing exhilarating music, conductor Ronald Braunstein wants “The audience to walk away feeling like, wow, people with mental illness can really work together and make something really, incredibly beautiful. Any stigma that I ever had for people with mental illness, I’m just so ready to let it go.”

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Orchestrating Change challenges the stigma associated with mental illness. It is these experiences that can help reframe how we see mental illness, and put the focus where it belongs, on the need to change society's misconceptions. If we can make the invisible disability more visible, perhaps we can begin to design crucial societal accommodations that allow for greater access and ultimately success.

3. A BRIEF HISTORY OF THE TREATMENT OF THOSE LIVING WITH MENTAL ILLNESS

In *Orchestrating Change*, several musicians share poignant stories of being hospitalized due to their mental illness. Most notably, we see both Dylan and Marek experience hospitalization during the course of the documentary. These frequent and/or extended stays make it challenging to maintain meaningful employment, hard to preserve social relationships and interfere with making it to orchestra practice. As a country, we have a history of, at best inadequate, at worst egregious treatment and support for those living with mental illness. Here is just a snapshot:

- **1841:** Boston schoolteacher, Dorothea Dix visits the East Cambridge Jail, where she first sees the horrible living conditions of the mentally ill. Believing they could be cured, Dix lobbies lawmakers and courts for better treatment until her death in 1887. Her efforts lead to the establishment of 110 psychiatric hospitals by 1880.
- **1887:** On assignment for *New York World*, Nellie Bly feigns lunacy in order to be admitted to the Women's Lunatic Asylum on New York's Blackwell's Island. Her exposé, "Ten Days in a Mad-house," detailing the appalling living conditions at the asylum, leads to a grand jury investigation and needed reforms at the institution.
- **1936:** Dr. Walter Freeman and his colleague James Watt perform the first prefrontal lobotomy. By the late 1950s, an estimated 50,000 lobotomies are performed in the United States.
- **1938:** Italian neurologist Ugo Cerletti introduces electroshock therapy as a treatment for people with schizophrenia and other chronic mental illnesses.
- **1946:** President Harry Truman signs the National Mental Health Act, calling for the establishment of the National Institute of Mental Health to conduct research into neuropsychiatric problems.
- **1954:** Marketed as Thorazine by Smith-Kline and French, chlorpromazine is the first antipsychotic drug approved by the Food and Drug Administration. It quickly becomes a staple in asylums.
- **1962:** *One Flew Over the Cuckoo's Nest*, a novel by Ken Kesey, is published. The bestseller is based on his experience working there as a nurse's aide in the psychiatric wing of Menlo Park Veteran's Hospital in California.

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- **1963:** President John F. Kennedy signs the Community Mental Health Act to provide federal funding for the construction of community-based preventive care and treatment facilities. Between the Vietnam War and an economic crisis, the program was never adequately funded.
- **1980:** President Jimmy Carter signs the Mental Health Systems Act, which aims to restructure the community mental-health-center program and improve services for people with chronic mental illness.
- **1981:** Under President Ronald Reagan, the Omnibus Budget Reconciliation Act repeals Carter's community health legislation and establishes block grants for the states, ending the federal government's role in providing services to the mentally ill. Federal mental-health spending decreases by 30 percent.
- **1990:** Clozapine, the first "atypical" antipsychotic drug to be developed, is approved by the FDA as a treatment for schizophrenia.
- **2010:** There are 43,000 psychiatric beds in the United States, or about 14 beds per 100,000 people - the same ratio as in 1850.

RESOURCES:

Pan, Deanna (2013). Timeline: Deinstitutionalization and Its Consequences. Mother Jones, Apr. 29, 2013

4. MENTAL ILLNESS AND CONTEMPORARY SOCIAL JUSTICE

In the medical field, anti-stigma programs tend to focus on education. These campaigns provide information about the biogenesis of mental illness, with the goal of taking the blame of mentally ill people by providing accurate facts about a given diagnosis. Such messages can backfire. Despite medical accuracy, the message can exacerbate attention to the "differentness" of those living with mental illness. Patrick Corrigan from University of Chicago reports that anti-stigma programs solely reflecting the medical perspective may have unintended consequences. The public may view mental illness as a genetic condition from which the person does not recover. It might foster pity rather than parity. It places responsibility for the stigma on the person with mental illness rather than where it belongs—on the public. When viewed in terms of the prejudice and discrimination experienced by other out-groups, such as ethnicity and gender, stigma is better understood as an issue of social injustice. On the basis of sociological research, a social injustice perspective argues that many of the lost opportunities experienced by people with mental illness result from the difference and defects suggested by stigma, and not due to lack of interest or talent. Exaggerated notions of group difference result in less power for people with mental illness. Most Americans would protest any policy that suggested the best way to deal with the prejudice experienced by gays and lesbians would be to correct their sexual orientation. Framing stigma as social injustice expands understanding of its impact, and can broaden the approach to eradicating stigma.

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Me2/Orchestra is different from other mental health or disability organizations because it is a model for how society can function when people with and without diagnoses work together and acceptance is the norm. Before each concert, Executive Director, Caroline Whiddon, advises the audience that this is a “stigma-free” zone. She challenges them to try to identify who is living with a diagnosis and who isn’t. Audiences are forced to abandon preconceived notions and simply hear beautiful music.

At concerts, audiences interact with the musicians. Sometimes it’s just to answer questions about their instruments. Other times, it’s to share their stories. At the final concert in the film, French horn player Carole, a Harvard graduate, stands before hundreds of people and explains that she was once afraid to tell potential employers about her mental illness. Today, she no longer has that fear thanks to the support of Me2/Orchestra.

RESOURCES:

Corrigan, Patrick (2004). How Stigma Interferes with Mental Health Care. *American Psychologist*, 59, 614-625

5. QUESTIONS FOR DISCUSSION

Before you watch the film:

- What are the first thoughts that come to mind when you hear the term “mental illness”?
- What are some of the factors that may have influenced your ideas about mental illness?
- How comfortable or uncomfortable are you talking about mental illness?
- How often do you come in contact with, and/or interact with individuals living with mental illness?
- What brought you to this film?

After watching the film:

- Were any of your ideas of mental illness challenged?
- As you watched the film, were there any social norms alluded to that may contribute to making the lives of the Me2/ musicians more difficult?
- As a child, Maestro Ronald and his parents were told he had “bad nerves,” what were some of the ways members of the orchestra had their mental illness marginalized?
- Why might someone not living with mental illness choose to join Me2/Orchestra?

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- Caroline said that she loved the shock when people heard the music before finding out about the mission of Me2/. As an audience member, how might knowing that 50% of the musicians live with mental illness affect your listening experience?
- Alana-Bethany said that at Me2/, she's treated on a "situational basis," instead of just someone who is mentally ill. What's the difference?
- Corey shares that she's able to bring together the two biggest parts of her identity, musician and having a mental illness. Is a diagnosis an identity?
- In the film, Sandy says that playing the flute makes everything go away because it takes up all parts of her brain. Do you think music is therapeutic or just a distraction?
- How different does conductor Ronald Braunstein seem when navigating a grocery store, versus taking the podium? Why might this be?
- Erik does not have a diagnosis, but knows a few of his family members do. Why might someone without a mental health diagnosis join an orchestra like Me2/?
- Carole talks about "coming out" as having a mental illness. What could the consequences be for those who decide to come out? What about for those who remain "in the closet"?
- Carole also talks about "self-stigma." How might societal norms about mental health disabilities additionally impact someone living with a mental illness?
- Dylan says there is nothing to understand, just to accept. What might he mean?
- Caroline discusses the stigma of mental illness on the radio with Vermont Public Radio host, Walter Parker, saying that that its sensational stories in the media that shape our ideas of what living with mental illness is like, instead of those people who get up every day to go to their full-time jobs and have wonderful families. How is mental illness portrayed in the media? How might this effect your understanding of mental illness?
- Why might people be more accepting of Dylan when he tells them he's addicted to drugs, instead of living with a mental illness? What does that say about society?
- As Corey leaves for grad school, how do you think being a member of Me2/ might help her succeed?
- For those patients residing at the Woodside Juvenile Rehabilitation Center, what might the lasting impact of hearing a Me2/ concert be?

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- On the stage door a sign reads, “Maestro. Please do not disturb. He is already disturbed.” Is humor appropriate when dealing with, or talking about, mental illness?
- Dylan’s mother, and Sandy’s parents are very emotional before the final concert. What impact do you think Me2/ has on the families of these musicians?
- Both Marek and Dylan take some time away from the orchestra, how do we create permeable spaces that allow for both presence and absence that provide peer support or distance when needed?
- How does Me2 Orchestra provide insight into mental illness as part of the normal range of human experience?

6. WAYS TO INFLUENCE

What can you do?

- Ask people how they prefer to refer to mental illness. Some people identify with their illness and some do not. It is better to have the conversation than to assume. Support organizations like Me2/Orchestra that look beyond diagnoses and work toward the eradication of social stigma.
- Attend cultural events designed to bring together diverse groups to show acceptance and inclusion.
- Demand that you local politicians and representatives talk about issues of mental illness and disability as part of social equity and justice, and not just health policy.
- Do research and ask questions. Broaden your understanding of mental illness and disability its impact on the criminal justice system, public education, child welfare , etc.
- Be a vocal advocate. Make sure those around you know that you support and accept those living with mental illness. It could make a huge difference in someone’s life.

7. RESOURCES

Articles:

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Mills, C. and Fernando, S. (2014) "Globalising Mental Health or Pathologising the Global South? Mapping the Ethics, Theory and Practice of Global Mental Health", *Disability and the Global South* 1(2).

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Books:

Anderson, J., Sapey, B. & Spandler, H. (2012) *Distress or Disability? Proceedings of a symposium held at Lancaster University, 15-16 November 2011*. Centre of Disability Research, Lancaster.

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Fernando, S. (2010). *Mental Health, Race and Culture* (3rd ed.). London: Palgrave Macmillan.

Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Anchor Books: New York, NY.

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LeFrançois, B.A., Diamond, S. (2014) *Psychiatry Disrupted: Theorizing Resistance and Crafting the (R)Evolution*. McGill-Queen's University Press, Montréal.

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Price, M. (2013) *Mad at School: Rhetorics of Mental Disability and Academic Life*. University of Michigan Press.

Read, J. & Reynolds, J. (1996), *Speaking Our Minds: An Anthology of Personal Experiences of Mental Distress and its Consequences*. Houndmills, New York: Macmillan.

Spandler, H., Anderson, J. & Sapey, B. (2015) *Madness, Distress and the Politics of Disablement*. Policy Press.

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8. ORGANIZATIONS

NAMI-National Alliance on Mental Illness

nami.org

Helpline: 800-950-6264

There are nearly 1,000 NAMI state organizations and affiliates across the US.

Depression and Bipolar Support Alliance

dballiance.org

800-826-3632

NIMH: National Institute of Mental Health (Information Resource Center)

nimh.nih.gov

1-866-615-6464 / toll-free 1-866-415-8051

National Suicide Prevention Lifeline

1-800-273-TALK

SARDAA: Schizophrenia and Related Disorders Alliance of America

sardaa.org

240-423-9432

NEABPD: National Education Alliance for Borderline Personality Disorder

borderlinepersonalitydisorder.org

International OCD Foundation

iocdf.org

617-973-5801

Mental Health America

mentalhealthamerica.net

9. CREDITS

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For more info about the film *Orchestrating Change*, please visit:

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