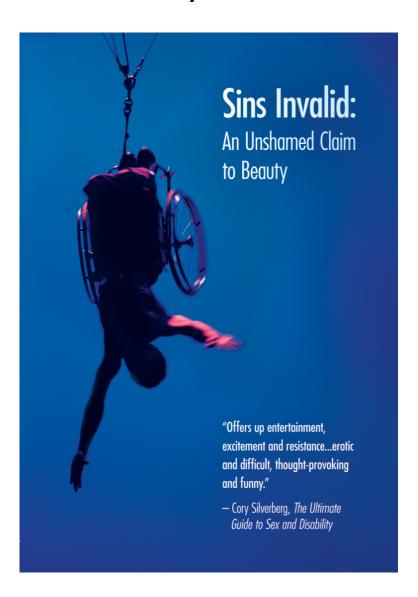
## Sins Invalid

## **Study Guide**



This study guide, compiled by both disabled & able-bodied folks, is intended to prompt discussion, curiosity, exploration, and community. We've attached suggestions for making your study group more accessible. Authors of the referenced works must be respected as artists and as thought leaders. Please visit the sites of these works, be they online or in books referenced in the study guide and, as is possible for you, buy copies to further support their incredible work!



#### Disease Is Not A Metaphor

Cyree Jarelle Johnson

Johnson, Cyree Jarelle. "Disease Is Not A Metaphor." Accessed February 10, 2014. <a href="http://www.blackgirldangerous.org/2013/07/2013729disease-is-not-a-metaphor/">http://www.blackgirldangerous.org/2013/07/2013729disease-is-not-a-metaphor/</a>.

- 1. Early on in Jarelle's essay, the reader is challenged to reflect upon the ways in which our everyday language whether speaking of being "'crippled' by debts" or "'paralyzed' by fear" often serves to reentrench able-bodied supremacy. What are some examples of ableist language that you find yourself or others within your communities using? How can we work to create a more intentional lexicon, one which serves to challenge rather than reinforce hegemonic conceptions of our bodies and their place in the world?
- 2. Jarelle's essay closes by stressing the importance of creating a world in which difference is acknowledged, affirmed, and celebrated rather than downplayed, hierarchically organized, or even violently stamped out: "And the body is not just like yours even though there are overlaps in desire and function. Sameness is not a prerequisite for solidarity." What implications does this radical embracing of difference carry for social movements working for liberatory change? In what ways do we find ourselves positing "sameness" as the "prerequisite for solidarity"? How does the fear of difference limit our ability to imagine a more just, egalitarian, and loving world?



## Looking Back but Moving Forward: The Radical Disability Model A.J. Withers

Withers, AJ. "Looking Back but Moving Forward: The Radical Disability Model," in *Disability Politics & Theory*. Halifax and Winnipeg: Fernwood Publishing, 2012.

- 1. Withers contends that "intersectionality," or "addressing multiple oppressions together and in conjunction with each other," is a foundational component of a radical disability model. According to Withers, contemporary disability movements and studies fall short of this ideal, tending to elevate certain arenas of oppression over others, or forcing individuals and groups to "choose" among identities and conditions. What are some concrete ways you have seen this tendency play out in your own experience? Which groups have generally been privileged by a more narrow approach to disability politics? Also, how is an intersectional approach more than simply "adding up" a person or groups multiple identities? How, for example, might it help us to understand not only what it means to be disabled and black, but also how one's disability is experienced through race?
- 2. Withers argues that disability is a social construction rather than a biological given, and that the classification of disability is really a means of normalizing and privileging some bodies while pathologizing, subordinating, and marginalizing others. They contrast this approach to the "social model," in which "disability" is seen as the additional oppression lumped on top of a biologically given "impairment." Draw out the differences between these two frameworks for thinking about disability. What are some of the political implications of using one framework of understanding over the other?



## Sins Invalid: Disability, Dancing and Claiming Beauty Patty Berne

Berne, Patty. "Sins Invalid: Disability, Dancing and Claiming Beauty," in *Telling Stories to Change the World*, edited by Rickie Solinger, Madeline Fox, and Kayhan Irani. New York: Routledge, 2008.

- 1. Berne talks about the importance of leadership development in Sins Invalid's hybrid performance-community organizing model, highlighting in particular the challenges of developing a radical disability politic in a context in which the broader left had barely begun to address ableism. What exactly do you think Berne means by "leadership development," and how does this priority show up in the performances discussed in this piece or shown in the film? How did prioritizing leadership development compel Sins Invalid to incorporate community organizing into its previously performance-centered process? What lessons can we take from this hybrid model and apply in our own creative or political work?
- 2. Much of Sins Invalid's creative work explores the relationships between sexuality, desire, and disability. Why is sexuality such an effective frame for fleshing out the politics of ableism and disability justice? Why has it been so important to able-bodied supremacy to invisiblize the sexuality of differently-abled bodies?



## Disabling Sex: Notes for a Crip Theory of Sexuality Robert McRuer

McRuer, Robert. "Disabling Sex: Notes for a Crip Theory of Sexuality," GLQ: A Journal of Lesbian and Gay Studies, 17.1 (2010): 107-117, p. 114.

- 1. How does McRuer speak to the intersections of queerness and disability? How are they similar? How do they differ? What possibilities does he see for disability pushing the boundaries of queerness?
- 2. How does Lezlie Fry's experience of "testing the borders of unfuckability" in queer settings speak to the ways in which disability challenges and complicates queerness? In what ways do queerness and disability challenge and complicate the construct of black masculinity in the scenes between Juba Kalamka and Leroy Moore?
- 3. What does McRuer mean when he says that "The privilege of belonging to the disabled category ....is rooted in stigma" (111)?
- 4. How do this privilege and this stigma play out in Patty Berne's experience of being "paraded around naked" in a school for people with disabilities and in Maria Palacio's experience of having authorities look at her body as "just another example of what a cripple looks like"? How does privilege based on stigma play out in Mat Fraser's performance of being knocked down by the messages with which society addresses him even when those messages appear to put him in the privileged categories of ability and beauty?



## The Body is Not an Apology

Sonya Renee Taylor

Taylor, Sonya Renee. "The Body is Not an Apology." Accessed January 28, 2014. http://www.sonya-renee.com/#!watch.

- 1. What does Sonya Renee Taylor mean by the word "apology"? How can a body be an apology? In what ways does our culture cause us to think about a body as an apology?
- 2. Discuss the ways in which the film works against the notion of the body as an apology.
- 3. Consider the following lines in the poem regarding the body: "It is not a broken thing to be mended, be tossed./The body is not prison; is not sentence to be served." What do these lines mean? In what scenes in the film does this meaning become manifest?
- 4. Consider the lines in the poem: "Praise./For the bend, twist, fall, and rise again, /fall and rise again." In what ways does the film visually communicate bending, twisting, falling, and rising? How does the film make you feel and think about disabled bodies bending, twisting, falling, and rising? How does your response differ from your response to disability in other venues?



### You Get Proud by Practicing

Laura Hershey

Hershey, Laura. "You Get Proud by Practicing." Accessed January 28, 2014. http://www.cripcommentary.com/poetry.html#PROUD.

- 1. Take a moment and think about the items, people or abilities that Hershey lists in her writing—"money, a handsome boyfriend (or girlfriend), a nice car; to be able to walk, or see, or hear; a caseworker, a doctor"—What kind of social values or statuses do they bring to people? What might be some of the prompts for people to desire for these social statuses or affiliations in order to be proud of themselves?
- 2. What's your own definition of "proud?" What's the relationship between "pride" and "shame?" In many cultures, being proud conflicts with the value of being humble. What do you think? Can someone be proud and humble at the same time?
- 3. Hershey talks about adding voices to the circle where "brothers and sisters are being held for blocking buses with no lifts." How does taking action and joining civil disobedience make people proud? How do collective social actions help with building pride as a community?
- 4. Brainstorm on different ways to practice getting proud. The practices can be the baby steps that you have taken or the ones that you have been interested in taking. Feel free to share your thoughts with the discussion group.



#### Freaks and Queers

Eli Clare

Clare, Eli. "Freaks and Queers." Exile And Pride: Disability, Queerness And Liberation. Cambridge MA: South End Press, 1999. 81-118.

- 1. "Queer and cripple are cousins: words to shock, words to infuse with pride and self-love, words to resist internalized hatred, words to help forge a politics (84)." Why do the words, "queer" and "cripple" shock people? Do you agree/resonate with Clare's approach in using these words to resist internalized hatred? Why and why not? How do you use words or expressions to show your politics?
- 2. To continue the conversation from You Get Proud By Practicing, when someone experiences physical or mental pain on a regular basis, how does the concept of "pride" work to address the experience of bodily pain?
- 3. Consider the audience' responses when seeing gender-variant performers or disabled performers on stage, what do Sins Invalid's performance and freak show share in common? How do they differ from one another?
- 4. Performer Leroy Moore acted as a naked patient accompanied by the presence of an actor who played a doctor in a few performances in the film. Clare writes, "...public stripping, the medical practice of stripping disabled children to their underwear and examining them in front of large groups of doctors, medical students, physical therapists, and rehabilitation specialists... (103)" What power dynamics do you see in Moore's performances? Do you play any parts in such dynamics as an audience? How does Moore's public stripping differ from what Clare describes?
- 5. Director Patricia Berne comments on how Sins Invalid's performance is about "...controlling the terms of debate, orienting the gaze, determining what and how we are being perceived." What impacts can taking control on stage by the actors and directors make? Can you name a scene(s) in Sins' Invalid's performance that stirred up emotions and challenged your perception of queer and/or cripple?



## Uses of the Erotic: The Erotic as Power from Sister Outsider

Audre Lorde

Lorde, Audre. "Uses Of the Erotic: The Erotic as Power." Sister Outsider. Freedom CA: The Crossing Press, 1984.

- 1. According to Lorde, what is erotic? What kind of resources or power does the erotic offer to women?
- 2. "Pornography emphasizes sensation without feeling (54)." How do you distinguish sensation versus feeling?
- 3. Why do people fear eroticism? What may be some of the social taboos that force people to fear of their true feelings?
- 4. Sins Invalid's performing artists express their erotic power through creative arts by making their narratives visible and confrontational, how has watching the film about queer and/or crippled bodies made you conscious about your sense of self (your body, sexual orientation, desire, intrapersonal and interpersonal relationships, etc.)? Which piece of performances spoke to you the most with its erotic power?
- 5. Lorde talks about "looking away" from the erotic and the harms that it brings. In Sins Invalid's performances, how do the performers direct the audiences' gaze and confront the human tendency to "look away?" (In other words, how do the performers draw your attention? What are some of the aesthetic elements that the performers use?)
- 6. Do you see the "erotic's electrical charge (59)" that Lorde describes in Sins Invalid's performances? How would you use your won words and describe the "erotic's electrical charge?" How does such electrical charge make you feel?



## selections from Mountain Moving Day, Drifting to Bottom, & Listen, Speak from *Kindling*

**Aurora Levins Morales** 

Levins Morales, Aurora. Kindling. Cambridge MA: Palabrera Press, 2013.

http://www.auroralevinsmorales.com/excerpts-from-kindling.html

#### p. 9-10, Mountain Moving Day

- 1. What is Levins Morales dismantling when she writes, "There is no neutral body"? What is she making space for in its wake?
- 2. What connections arise for you in considering how our body and the earth require the same things to thrive? What power can be found in those connections?
- 3. How can illness bring clarity?

#### p. 163, Drifting To Bottom

- 4. What are some common assumptions about what/who is sexual or sexy? What about what sex is and how it looks?
- 5. How does this piece relate to "The Erotic as Power"?

#### p. 165-167, Listen, Speak

6. What do you feel Levins Morales is calling for in this piece?



## **Access Suggestions**

(for Study Group or Public Event)

Everyone has needs to make an event accessible to them – free time, possibly money, childcare, transportation and cost, language access, disability related access, appropriate written materials, etc.

This guide is intended to help you think through some ways to engage a spectrum of people with and without disabilities in doing a public event. But please note, these suggestions are not comprehensive! Each item will hopefully prompt you to think through the cascade of access barriers in the world and how we can best disrupt them to create "liberated zones" from disability oppression. Many of the suggestions may also useful within organizational processes as well. We'd love to hear your additions/feedback at info@sinsinvalid.org.

#### GENERAL GUIDANCE REGARDING ACCESS

- Access for all community members takes time as well as commitment. In general, the more lead time the better for making a gathering or event accessible to everyone, so the longer in advance you consider these issues, the more likely you can address them. Improving access is always a process in development and we've got to start where we are! So wherever you are is a great place to start and please incorporate what you can from these suggestions and next time incorporate a little more © This is how we grow together...
- We live in a capitalist ableist world. That means that unfortunately there is often a price tag that goes along with access. Individuals with disabilities should not be responsible for this cost. For organizations with budgets, we know they reflect what we prioritize travel or salary or room rental costs or whatever. Reflect your politics and make line items for access needs in your budget. Know that some access needs may be expensive and have Plan B's to ask for help in securing that service/agency/etc if your budget can't reflect what you want.
- Remember, everyone has needs to make an environment accessible to them, and people will definitely know best what their specific needs are! So in general, your promotion material should state what access needs

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have been addressed (i.e. ASL interpretation, wheelchair access, etc) and state that people can write or call to request specific access needs. Some events will allow for the organizers to ask folks what they need to participate – also a great place to start!

- Access needs can be shared and talked about without shame 

  We can't assume that our friends or colleagues or even our families will know our access needs that we need to be warm or we're in pain, that we need information given to us in this way or that, that we're feeling tired on a given day so we can't walk far, etc. At Sins Invalid, we try to practice speaking up about what our access needs are, in the hopes that perhaps others can help meet those needs.
- Access support can be shared. Encourage people to think about what access needs they have, and also what access needs they can help meet for others. Some access needs may be specific, and may need a person skilled in a particular field (i.e. an ASL interpreter or some personal care), but other types of access support can be shared (i.e. notetaking or making plates of food).
- Try to hold compassion in the process. Sometimes, even with the best planning, some access needs go unmet. A little humility goes a long way in holding the frustration a person experiences when their needs are not met.
- Have an access committee for planning purposes and a person or two be the "access coordinator(s)" on the day of the event if you anticipate the gathering to be more than 15 people. They can handle access planning before hand and address access related issues on the day, help troubleshoot, and in general be thinking about it and available to respond.

#### SPECIFIC ACCESS ITEMS TO CONSIDER INCLUDE

• <u>Different forms of outreach</u>: Some people respond best to talking, some people to reading, some to face to face interactions. How are you communicating about the gathering? People often use email and Facebook, but perhaps incorporate phone trees, texting and face to face invites if you can!



For written material, try to use Arial or other plain, sans serif fonts, at least 14 point font, black ink on white non-glossy paper, and check out these links for additional suggestions please visit:

http://webaim.org/techniques/alttext/

http://www.un.org/webaccessibility/1\_visual/13\_colourcontrast.shtml

- <u>Non-Visual Options</u>: Audio describers describe action on for folks who are visually impaired. Will this be helpful for participants in your event? Is a trained Audio Describer available for your event? If not, is someone who can see and describe without commentary available to do informal audio description? Also, if you are giving directions to the gathering site, can you think through how best to explain it to a person with a visual impairment?
- <u>Bathrooms</u>: Folks may well need to use the restroom during your event. There are long histories of trans and genderqueer people being harassed and in danger when they go into bathrooms, and equally long histories of folks with mobility impairments not being able to access bathrooms due to architecture, and still more history of folks with chemical injuries getting ill from the chemicals used in cleaning bathrooms. If possible, it's helpful to actually go to the public site, see the bathroom and speak with the management. Is there a toilet that is in a bigger stall, that is lowered and/or with a grab bar for folks with mobility impairments? If not, make sure to let folks know in advance of the get together so they can take care of business at home! Is there a "gender neutral" bathroom? If not, can you hang a sign on one for the day that says "Gender Neutral"? Does the site use unscented cleaning products? If not, can they do it for a week before the date of the viewing?
- <u>Non-auditory options</u>: It's important to arrange for ASL interpretation at public events, and to announce to folks that there is ASL interpretation in your promotion if you do have it.
- <u>Food options</u>: If food is part of the gathering, it's great to have multiple options vegetarian, vegan, high protein (including meat), gluten-free, sugar-free, etc. Post ingredients somewhere visible and read them out loud before people start serving. If people have food allergies or dietary restrictions, invite them to let others know what they can eat. If possible, let people know in advance if there will/will not be food for the group so people can plan accordingly.

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- Wheelchair and other mobility-related access: We've all seen the little blue wheelchair symbol, but that doesn't help to break down mobility needs. Good things to consider include: Is there a working elevator? Are there steps or a steep slope in the building so that access may be limited? For folks where distance can be an issue, is Point A far from Point B? If there are doors to open and close to enter the site, are they heavy? If there is a bell or buzzer, who will or won't be able to reach it? Are there enough chairs for people? Are there wide chairs? There can be a lot of elements to troubleshoot, which is a good reason to have an access coordinator on the day of.
- <u>Scents and chemicals</u>: Can participants be encouraged to avoid scented products (commercial detergents, shampoo, soap, perfume) before the event? Is the space free of air fresheners, scented soaps, and other scented products? For outreach materials, consider a phrase like this "In order for beloved community members with chemical injury to attend, please don't use fragranced products." Given the way that scent moves, consider a fragranced area and a scent free area in your event. For guidelines on how to make your event accessible to people with Multiple Chemical Sensitivities (MCS), please visit http://vanessahuang.com/fragrance-free/.
- <u>Video Conferencing</u>: Do folks need to be in the room? Sometimes not, and you can provide the option of Google chat or Skype for those who can't be there in person.
- <u>Lighting</u>: Fluorescent lighting can trigger seizures and can make spaces less accessible for people with sensory issues and/or neurological diversity. Are other options (like lamps) available? Has there been discussion of flash photography? If not, ask for consent from all participants as the flash can trigger seizures in some.
- <u>Structured schedules and awareness of time</u>: When organizing, it's always good to be aware of time it's important that people know the schedule and that you try your best to stick to it (with flexibility and reason ©) for lots of reasons! Attention and information processing needs, prescheduled transportation, schedules with assistants, childcare schedules and more can be elements that may impact someone's ability to stay for the "program". We can never assume people can stay an hour later if



we're not on schedule! If there have to be schedule changes, let people know and be as clear about them as possible.

- <u>Language access</u>: Everyone communicates in the way most familiar to them. When you are inviting people to the gathering or having the discussion, will everyone know what you are saying? Are you using words most people will know? If not, can you explain those terms? Check in with folks would it be helpful for people to say their name before they speak? Are interpreters (e.g. ASL, Spanish, Tagalog, etc) possibly available for the event for community members who have a language other than English as their first language?
- Access to quiet space: It can often be helpful to have a space where people can go if they need to be alone/with less stimulation. Do you have the space and flexibility so that people can step back if they are getting overstimulated or tired?
- <u>Transportation</u>: How are people arriving? Can people rideshare? Is there public transportation that would dovetail with the time of the viewing? Does paratransit need to be called?
- <u>Identities and experiences</u>: Are folks aware of people's preferred gender pronouns (not everyone goes by he/she or him/her, and we can't assume based on presentation)? Similarly, remember that not all disabilities are visible, and some people may choose not to disclose a disability.
- Be upfront about remaining known barriers.

Some of this guide has been adapted (with permission and gratitude) from Cripchick's blog at http://blog.cripchick.com/archives/2910.