Sins Invalid

SINS INVALID DISABILITY LIBERATED
VIEWERS PACKET

Dear Fabulous Viewers and Bad-Ass Hosts of Viewers,
Thank you for supporting Sins Invalid and viewing and / or organizing a Disability Liberated viewing party in your community!

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    - o "Disabling Incarceration: Connecting Disability to Divergent Confinements in the USA" by Liat Ben-Moshe, *Critical Sociology*, 20 Dec 2011
    - o "From Disability to Criminality Infographic" by Erin Zipper and Julianne Hing, *Colorlines*, 13 May 2014
    - o "Disablement, Prison, and Historical Segregation" by Jean Stewart and Marta Russell, *Monthly Review*, July 2001
- ➢ The Sins Invalid brochure

VIEWING NOTES – Thank you for watching!
- ▪ We're asking individuals to pay $4 - $10; we ask each viewer to support Sins by stretching an additional $5 to your contribution
- ▪ If you are viewing in a group, please times $4 by the number of people viewing
- ▪ The sliding scale begins at $0 for those unable to pay
- ▪ Payment is via PayPal, linked on the video page
- ▪ Disability Liberated will be available to watch any time, day or night, on demand, beginning Oct. 9th 2015 http://dualpowerproductions.com/sins-invalid/
- ▪ The web streamed live Q&A will happen on Sun, Oct. 11th, 8p PST / 11p EST

Happy viewing!
Your friends at Sins Invalid

ACCESS SUGGESTIONS FOR A 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 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 trouble shoot, and in general be thinking about it and available to respond.

SPECIFIC ACCESS ITEMS TO CONSIDER INCLUDE

• Different forms of outreach: 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

• Non-Visual Options: 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?

• Bathrooms: 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 outloud 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.

• <u>Wheelchair and other mobility-related access</u>: 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 trouble shoot, 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 can 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 inaccessible 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.

• Structured schedules and awareness of time: 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, pre-scheduled 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 late on schedule! If there have to be schedule changes, let people know and be as clear about them as possible.

• Language access: 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?

• Transportation: 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?

• Identities and experiences: 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.

Come. You. Yes, you.
Tonight we are gathering stories, ours, yours.
Each of us with our bundles of sticks, each of us with our strands of cord.
The word in your pocket is what we need.
The song in your heart, the callous on your heel.

Come out of the forest, the woodwork, the shadows to this place of freedom
quilombo, swamp town, winter camp, yucayeque
where those not meant to survive laugh and weep together
share breath from mouth to mouth, pass cups of water, break bread
and let our living bodies speak.

Our history is in our bodies
what we do to breathe, how we move, the sounds we make
our myriad shapes, our wild gestures
far outside the boundaries of what's expected
the knowledge bound into our bones, our trembling muscles, our laboring lungs
like secret seeds tied into the hair of our stolen ancestors
we carry it everywhere.

Come beloveds from your narrow places
from your iron beds, from your lonely perches
come warm and sweaty from the arms of lovers
we who invent a world each morning
and speak in fiery tongues.

Come you with voices like seagulls
dissonant and lovely, with hands like roots and twigs.
Come limbs that wander and limbs like buds and limbs heavy as stone
come breathless and swollen and weary, fevered and wracked with pain.
Come slow and heavy, come wary and scarred, come sweet and harsh and strong. Come arched with pleasure,
come slick with honey
come breathless with delight.

We say with our feet, with our backs and hands
no life belongs to another, our bodies are not acreage
livestock, overhead, disposable tools.
We hum as we travel, songs heavy with maps that lead us back to ourselves
singing you, yes you, are irreplaceable.

Here we are, and here we are fruitful
our stories flower, take wing, reproduce like windblown seeds.
No surgeon's knife can cut the lines of spirit.   Our family tree remains.

-    *from* "Listen, Speak" in *Kindling: Writings On the Body* by Aurora Levins Morales

Disability Liberated is not a passive grieving, but a furious mourning, an elegy to all that we have lost, and a promise to fight like hell for all that survives.

Disability Liberated was born out of collective struggle. We sought first and foremost to pay homage to the countless disabled lives that have been lost to the violence of able-bodied supremacy, whether that loss be corporeal – souls robbed of their very embodiment by state, vigilante, or, too often, intimate violence – or the loss of freedoms through incarceration in prisons or other disciplinary institutions. Our understanding of able-bodied supremacy has been formed in relation to intersecting systems of domination and exploitation. The histories of white supremacy and ableism are, after all, inextricably entwined, both forged in the crucible of colonial conquest and capitalist domination. We cannot comprehend ableism without grasping its interrelations with heteropatriarchy, white supremacy, colonialism, and capitalism, each system co-creating an ideal bodymind built upon the exclusion and elimination of a subjugated "other" from whom profits and status are extracted.

Disability Liberated keeps these connections front and center, drawing upon the legacies of cultural and spiritual resistance within *vodou* that confronted and subverted colonial powers along a thousand underground paths, igniting small persistent fires of rebellion in everyday life. In an historical moment in which Black communities around the country have been rising up against police violence and asserting claims to worth, dignity and power, disabled people of the global majority -- black and brown people -- share common ground in our struggle for life and justice. 500+ years of violence against black and brown bodies includes 500+ years of bodies and minds deemed *dangerous* by being non-normative – *"deviant", "unproductive", "invalid."* We know that there has always been resistance to all forms of oppression, as we know through our bones that there have simultaneously been disabled people visioning a world where we flourish, that values and celebrates us all in our diverse beauty.

Disability Liberated is an intervention into a landscape of absences. For if the ruthless violence of able-bodied supremacy were not bad enough, we also find ourselves confronted with the myriad ways in which ableism renders this violence invisible. Seldom do we find mainstream discussions of the fact that people with disabilities are disproportionately subjected to police violence, nor do we hear of the scores of children with disabilities that are abused, neglected, even caged as unhuman, murdered by their families or "caregivers" for failing to perform able-bodiedness. Similarly invisible is the callous herding of people with disabilities into jails, prisons, and institutions such as "nursing homes," "psychiatric facilities," and "rehabilitation centers" that the volume *Disability Incarcerated* rightly names as sites of segregation and confinement within a vast and growing "carceral archipelago." Just as we can trace the origins of the police to slave patrols, the coercive warehousing of people with disabilities and the rampant violence visited upon us today is rooted in eugenics, forced sterilization, and outright genocide.
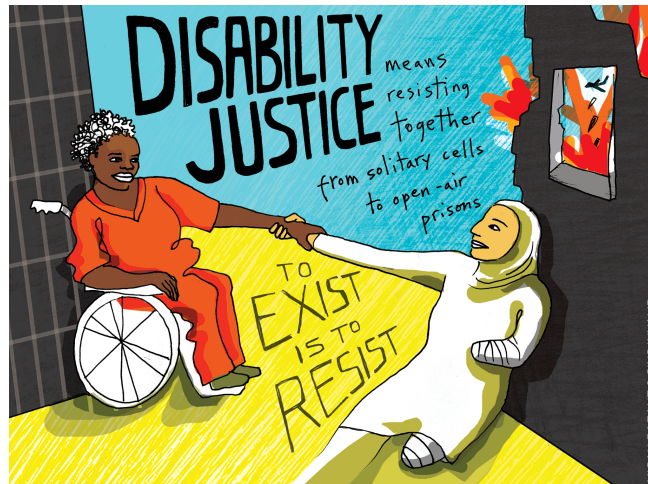
Disability Liberated is a rebellion against attempts to invisibilize this violence, an honoring of the longstanding legacies of resilience and resistance which are the inheritance of all of us whose bodies or minds will not conform. As such, we acknowledge the fact that *Disability Liberated* takes place on stolen Chochenyo Ohlone land, which is a site of the ongoing colonizing acts of the University of California -- right here, where you sit and stand and read this text is only yards away from a whole host of stolen artwork, cultural artifacts, and essentially on top of ancestral Ohlone people, stored in drawers, detained awaiting "cataloguing". The University of California is blatantly trampling upon the rights of Native communities to dignified mourning, in violation of the Native American Graves Protection and Repatriation Act passed by the US Congress in 1990. Alfred Kroeber, after whom this building is named, is the colonizing anthropologist who wrote that Ohlone tribes were "extinct so far as all practical purposes are concerned" (The Handbook of California Indians, 1925), single handedly terminating their ability to obtain federally recognized status, making the Ohlone peoples landless. These actions disdain the humanity of Native communities and are a part of normalizing 500 years of settler-colonial violence and genocide of the indigenous peoples of this continent.

We feel the historical weight of our accumulated losses and Sins Invalid wishes to acknowledge the enormity of loss that confronts Native communities, and to express our solidarity with Native students and community groups that are struggling for the just repatriation of what is rightfully theirs. While we grieve what has been lost, we also celebrate we who remain, and struggle towards what is yet-to-be. Disability justice is a vision and practice of this yet-to-be, a map that we create with our ancestors and our great grandchildren onward, in the width and depth of our multiplicities and histories, a movement towards a world in which every body and mind is seen as valuable and beautiful.

-   Sins Invalid

> *We unwrap our tongues, we bind our stories, we choose to be naked*
> *we show our markings, we lick our fingers, we stroke our bellies*
> *we laugh at midnight, we change the ending*
> *we begin, and begin again.*

-   *from* "Listen, Speak" in *Kindling: Writings On the Body* by Aurora Levins Morales

DISABILITY JUSTICE means resisting together from solitary cells to open-air prisons

TO EXIST IS TO RESIST

MICAH BAZANT & SINS INVALID

Sins Invalid is a disability justice-based performance project centering disabled artists of color and queer / gender non-conforming disabled artists. Our work celebrates the embodied humanity of disabled people, and we understand all bodies live in a multitude of very real social, political, economic and cultural contexts.

As an organization led by disabled people of color and queer / gender non-conforming people with disabilities, we live with high rates of state violence, from forced institutionalization, to ongoing police brutality and the murder of Black and brown disabled people.

We witness the horror of a deadly chokehold placed on Eric Garner, a Black man with multiple disabilities, by the NYPD. We hear the cries of Ezell Ford's mother when she realized that her son with mental health disability was shot by LAPD while walking home. We stand with Lashonn White, a Deaf queer Black woman who was running toward police for safety, and instead tased by police and jailed for three days without access to an interpreter. We feel rage with the family of Kajieme Powell, a Black man with a mental health impairment, who was shot by St. Louis police within seconds of their arrival, for stealing two sodas and a package of pastries.

We know that modern day police forces are direct descendants of the "slave patrols" employed to police and control the bodies and labor of enslaved African people and violently repress their resistance to slavery. We recognize that Black and brown people with disabilities are pipelined from "special education" to incarceration of one form or another.

We acknowledge that disabled people who are Autistic, who are Deaf, who live with mental health impairments, or cognitive impairments, epilepsy or movement disorders, are at highest risk of being assaulted by

police, and that this is deeply compounded when we are further marginalized by homelessness, transphobia, and white supremacy.

We do not see training as a viable solution, since it leaves intact the fundamental belief of the police that their purpose is to "control the situation." As people with disabilities, our bodies and minds are not controllable and cannot always comply — this must be understood. Our bodies and minds are not criminal. We are unique and we celebrate our complexities.

We grieve that people with disabilities have largely been ignored and dismissed as key leaders in resistance to state violence by the US Left, perpetuating the silencing of our stories and maintaining barriers to a united front.

It is within the context of disability justice that we hold true that all communities are valuable and that we **DEMAND AN END TO POLICE VIOLENCE!**

Content Information: We want to remind our beloved audiences that this performance is distinct from other Sins Invalid performances, as it focuses on violations of our body/minds, whereas our usual performances focus on embodiment, sexuality, and celebration. Given that, please be aware that there is graphic discussion of family, interpersonal, institutional and state violence in the performance and films. We trust and encourage you to take good care of yourselves and each other, always. For more content information, please review the performance program.

Sins Invalid

SINS INVALID DISABILITY LIBERATED
**POST-VIEWING DISCUSSION QUESTIONS**

We hope these questions will generate thought and discussion. Choose three or four that are a good match for you / your group and take them in any directions you want!

- ✓ What resonated with you from this performance? What feelings came up? What feelings arose in your body? How did these shift throughout the program?

- ✓ Were your experience reflected by the performers, the soundscapes, the images or the films? Why or why not?

- ✓ When did you feel uncomfortable? Why? Which pieces felt problematic? Why?

- ✓ What assumptions have you made about incarceration or policing? Have these assumptions been challenged or transformed? If so, how?

- ✓ How are incarceration and policing disability justice issues?

- ✓ How do ableism and heteropatriarchy (amongst other things) co-create family abuse?

- ✓ Please talk about what social structures and/or systems could be in place that would make full de-institutionalization and prison abolition possible and successful?

- ✓ How can the acceptance of our bodies be radical? What limits our abilities to do this?

- ✓ In the context of powerful black-led actions against police violence across the country, how can we express the relationships between ableism, police violence, and mass incarceration in a way that expresses solidarity with #blacklivesmatter, that supports cross-movement building, and which remains grounded in a disability justice politic? Where are the openings and opportunities? Where are the tensions or pitfalls? What does it mean to engage with political integrity in this moment?

DISABILITY
LIBERATED

*MOURN THE DEAD
AND FIGHT LIKE HELL
FOR THE LIVING*
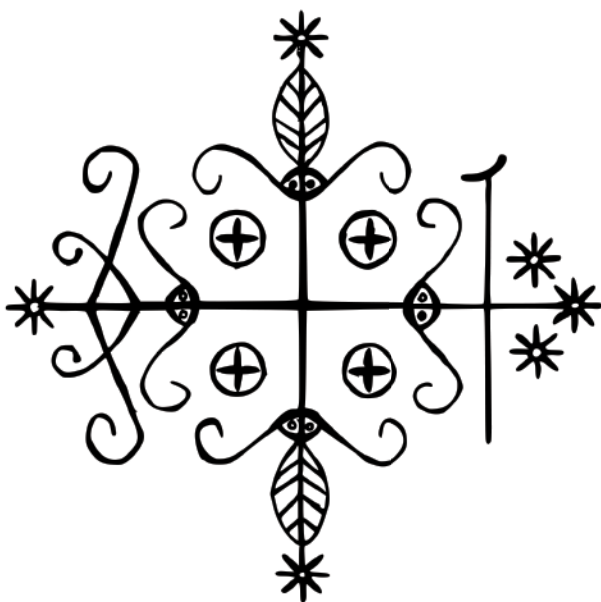
We present *Disability Liberated* to center the stories and voices of people surviving violence within the intersections of ableism and the prison industrial complex. *Disability Liberated* is a furious mourning, an elegy to all that we have lost, and a promise to fight like hell for all that survives.

Our understanding of able-bodied supremacy has been formed in relation to intersecting systems of domination and exploitation. The histories of white supremacy and ableism are inextricably entwined, both forged in the crucible of colonial conquest and capitalist domination. We cannot comprehend ableism without grasping its interrelations with heteropatriarchy, white supremacy, colonialism, and capitalism, each system co-creating an ideal bodymind built upon the exclusion and elimination of an "other".

Disability Liberated was created by Sins Invalid, a disability justice based performance project that celebrates artists with disabilities, centralizing artists of color and queer and gender-variant artists. For more info about Sins Invalid visit sinsinvalid.org or contact us at info@sinsinvalid.org.

PARTICIPATING ARTISTS

KIYAAN ABADANI has been advising Sins Invalid since 2013. They are a visual artist, political writer, and community activist committed to performance art as a path toward collective healing. Kiyaan identifies as a diasporic Iranian transboi... a tenderqueer krip who loves science-fiction, tea, astrophysics, and storytelling.

MICAH BAZANT is a visual artist and graphic designer who works with social justice movements to make change look irresistible. He also lives with depression, identifies as timtum (one of six jewish gender categories), and works with Sins Invalid as an artist and Advisory Board member.

PATRICIA (PATTY) BERNE is a Co-founder of Sins Invalid and currently contributes as its Executive and Artistic Director. Patty is a contributing writer for many Sins Invalid shows and recently directed the 32 min documentary about Sins Invalid (2013). Berne's experiences as a Japanese-Haitian queer disabled woman provide grounding for her work creating "liberated zones" for marginalized voices.

LISA GANSER is an artist, activist and odd jobber from Minneapolis that lives in San Francisco with mental illness and brain injury. They are an established filmmaker and provide access support for Periwinkle Cinema and the Idriss Stelley Foundation. The song Stars Out is part of a People's Investigation into the Wrongful Death of Asa Sullivan. www.ganserlamm.bandcamp.com

TODD HERMAN, Co-founder and advisor to Sins Invalid, makes and exhibits short films. His work deals with themes of the body and transience; sexual and representational taboos; spectatorship and complicity. He has been the recipient of numerous awards for his work and has presented his films at such venues as the International Film Festival Rotterdam, San Francisco International Film Festival, Southbank Centre, Anthology Film Archives, San Francisco Cinematheque, and Pacific Film Archives. For more information visit www.todd-herman.com

DAMON JOHNSON is incarcerated in the so-called California Department of Corrections and Rehabilitation at Salinas Valley State Prison. Convicted 26 years ago of a crime he didn't commit, Damon was sentenced to nearly three decades in prison.

NOMY LAMM is a writer, musician, and voice teacher who lives in San Francisco. She is on staff with Sins Invalid, writes regularly for The Body Is Not An Apology (thebodyisnotanapology.com), and has an advice column in Make/Shift magazine (makeshift-mag.com). "Maggie Remembers" is based on a chapter from her experimental novel, *515 Clues*.

OLEGARIO MARTINEZ is a first generation Chicano visual artist with two sons and a hope to see them soon. He has recently been approved for parole from the Jordan Unit in Texas, though his time of actual release remains uncertain.

LEROY F. MOORE JR. is a Co-founder of Sins Invalid and its Community Relations Director. Leroy is a contributing writer and performer for Sins Invalid shows. Leroy is currently writing a Krip-Hop book with Professor Terry Rowden and working on his poetry/lyrics book, *The Black Kripple Delivers Poetry & Lyrics* that will be out in early Summer of 2015.

FELICIA VASQUEZ is 38 year old woman of Arab & Puerto Rican descent, currently incarcerated at the Central California Women's Facility in Chowchilla. She is due to be released in 2016.

SINS INVALID WOULD LIKE TO EXPRESS ITS GRATITUDE TOWARD:

In Our Own Voice:

African-American
Stories of Oppression, Survival and
Recovery in Mental Health Systems

by Vanessa Jackson

Part 3 of the "It's About Time:
Discovering, Recovering and Celebrating
Psychiatric Consumer/Survivor History"

In Memory of
Julius Green and Michelle Jackson
whose lives and deaths remind me of the continued need
to tell the truth about suicide in the African-American community.

The author recognizes that language is important and political. Those of us who have been labeled by the psychiatric community have been denied a choice in how we are presented to the world. Through our liberation struggles, we have created our own identities as consumers, survivors and ex-patients, users and recipients. For the purpose of this tool-kit, I will use the term *survivors* to describe individuals who have received a psychiatric label. In describing what mental health professionals describe as mental illness, I will use the terms *mental illness, emotional distress* or any term used by an interviewee.

An Introduction

As a child, I frequently dodged the bricks thrown by my elderly great-grandmother, a small, dark, wiry woman, as she guarded her front porch. By professional standards, my Grandma Etta was probably mentally ill, suffering from extreme paranoia and an intense hatred of white people. On the days that I could get close to her, I could hear her muttering about blue eye devils and her favorite target of attack was a blond-hair, blue-eyed teacher who frequented my family's restaurant, which unfortunately was attached to her house. In her mid-seventies, my great-grandmother was moved to a nursing home after it was determined that she was completely blind (and probably had been for some time). She died less than two weeks after being admitted to the nursing home. Her death did not surprise me because I could not imagine her being contained in any space that she did not control.

I was young then, wrapped up in my own life and struggling with the embarrassment I felt when people made fun of Grandma Etta by calling her "crazy." It was years later that I began to look through boxes of family pictures and see the world of rural Missouri where she grew up. I really thought about the fairness of my grandmother's skin and wondered if there was some connection with my great-grandmother's hatred of "blue-eyed devils." I visited her hometown many years later—afraid to get out of my car in this rural, white world—and wondered how her "paranoia" may have kept her safe in this hostile territory.

I start with my grandmother's story because it reminds me of the importance of understanding a person's history before judging behavior. Context is everything, and that is a poorly understood principle in the history of psychiatric treatment. Grandma Etta escaped the oppression of a psychiatric label and the treatments that are frequently imposed after the labeling process. Other members of my family, myself included, were not so lucky. I offer libations to Grandma Etta for escaping the bonds of psychiatric labeling and to my sister, Michelle Yvette Jackson, who was not so lucky and who committed suicide in June 1984 after a four-year struggle with depression and life.

Alice Walker, in her poem, *Dedication* (Walker 1991, p. 313), reminds us of the need to collect all of the threads of our past when we sit down to create a quilt that represents the lives of African-American people. This excerpt from that poem captures for me the need for us to hear and value all stories as we continue to move forward in our struggle to liberate and heal those of us who identify as African-American mental health consumer/survivors /ex-patients.

> *"Rest in peace.*
> *The meaning of your lives*
> *is still*
> *unfolding.*
>
> *Rest in peace.*
> *In me*
> *the meaning of your lives*
> *is still*
> *unfolding.*
>
> *Rest in peace, in me.*
> *The meaning of your lives*
> *is still*
> *unfolding.*
>
> *Rest. In me*
> *the meaning of your lives*
> *is still*
> *unfolding*
>
> *Rest. In peace*
> *in me*
> *the meaning of our lives*
> *is still*
> *unfolding.*
>
> *Rest."*

The telling of stories has been an integral part of the history of people of African descent. From the *griots* of ancient African to the sometimes painful lyrics of hip-hop artists, people of African descent have known that our lives and our stories must be spoken, over and over again, so that the people will know our truth.

History, or at least the official record, is always the history of the dominant group. In America, the history of mental illness had traditionally been told in a voice that is white, rich, heterosexual, middle-aged, medical/professional and, of course, certifiably sane. This version of history has African- Americans as incapable of sufficient humanity to experience a mental crisis or rendered mentally ill by freedom or financial security. The official version, if it acknowledges our existence at all, tends to include us as a footnote or as a faded photograph. Rarely are our stories told of our lives before, during and after our mental health treatment. *In Our Own Voice: African-American Stories of Oppression, Survival and Recovery In Mental Health Systems* is a revolutionary act of self-love and a demand for visibility for African-American psychiatric survivors. We will acknowledge the painful truth that our invisibility has not been limited to the pages of history but is alive and well in our families and communities. As we listen to the voices of the men and women who shared

their stories we will hear the profound pain caused by mentalism and discrimination in our most important relationships, including our relationships with mental health providers. This guide and the sharing and connections that I hope will emerge from its use, will provide us with an opportunity as survivors to own our wounding and recovery and offer our experiences as lessons to our community on survival and triumph.

As I was preparing to write this introduction, I spoke with the daughter of one of the women interviewed as part of the oral history project. The daughter recounted her mother's delight at being asked about her history as a psychiatric survivor. I was humbled by the mother's response because I knew that it came out of a long history of being continuously asked about symptoms but never about her life. I remembered the interview and my amazement at this incredible woman's courage and resilience as she struggled with mental illness as a working class Black woman in a rich, white resort town in the 1950s. This conversation reminded me of the primary value of collecting history, especially oral history—the power of "restorying," or restoring our lives to a state of wholeness. Therapy has been a poor attempt at giving people the space to put their lives in context and the power to bold or underline the events and people that *we* feel are important to us. *In Our Own Voice* challenges each of us to take responsibility, if only by sharing our own story of survival and recovery, of creating a history that truly speaks in our own voice.

This guide is divided into four sections:

- Chapter I will provide some historical highlights regarding African-American survivors and mental health treatment in America.

- Chapter II will explore the themes shared in the oral histories collected in this initial phase of the project and provide a guide to collection oral history in your community.

- Chapter III will provide strategies for using history projects as a tool for personal and community healing and social change.

- Chapter IV will include resources to assist you in starting your own history project.

Chapter I: Freedom Made Us Nuts

A review of the history of mental health includes few references to the African-American experience. Robert Meinsma's *Brief History of Mental Therapy* offers a review of philosophical and medical views on mental illness dating back to 600 BC that includes nearly a thousand entries. However, this very comprehensive document boasts fewer than five entries pertaining to the experiences of people of African descent. A similar criticism can be offered of the timeline compiled by the American Psychological Association (Street, 2001). African-Americans have a presence in America dating back to at least 1619 when the first African indentured servants arrived in America (Bennett 1993). This chapter attempts to supplement the official records by offering a few accounts of African-American psychiatric survivors' experiences, and the philosophy and policies that guided the treatment of our ancestors and which still influence our treatment today.

A review of the history of African-American psychiatric survivors would quickly disabuse a reader of the notion that the process of recording history is apolitical. One of the earliest records dealing with the issue of insanity among African-Americans was in 1745 when the South Carolina Colonial assembly took up the case of Kate, a slave woman, who had been accused of killing a child. After being placed in the local jail, it was determined that Kate was "out of her Senses" and she was not brought to trial. However, the problem of how to care for Kate was an issue since her owner was too poor to pay for her confinement and South Carolina had made no provision for the public maintenance of slaves. Ultimately, the colonial assembly passed an act that made each parish in the colony responsible for the public maintenance of lunatic slaves whose owners were unable to care for them (McCandless, 1997). Not surprisingly, there is no further record of what happened to Kate or what circumstances led to the murder of the child.

Scientific Racism

Benjamin Rush, MD (1746–1813), signer of the Declaration of Independence, Dean of the Medical School at the University of Pennsylvania and the "Father of American Psychiatry," described Negroes as suffering from an affliction called *Negritude,* which was thought to be a mild form of leprosy. The only cure for the disorder was to become white. It is unclear as to how many cases of Negritude were successfully treated. The irony of Dr. Rush's medical observations was that he was a leading mental health reformer and co-founder of the first anti-slavery society in America. Dr. Rush's portrait still

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adorns the official seal of the American Psychiatric Association. However, Dr Rush's observation—"The Africans become insane, we are told, in some instances, soon after they enter upon the toils of perpetual slavery in the West Indies"—is not often cited in discussions of mental illness and African-Americans, however valuable it might be in understanding the traumatic impact of enslavement and oppression on Africans and their descendants. (Rush, 1813, p. 41)

In 1851, Dr. Samuel Cartwright, a prominent Louisiana physician and one of the leading authorities in his time on the medical care of Negroes, identified two mental disorders peculiar to slaves. *Drapetomia,* or the disease causing Negroes to run away, was noted as a condition, "unknown to our medical authorities, although its diagnostic symptom, the absconding from service, is well known to our planters and overseers." (Cartwright, 2001, p. 1) Dr. Cartwright observed, "The cause in most cases, that induces the Negro to run

away from service, is such a disease of the mind as in any other species of alienation, and much more curable, as a general rule." (Cartwright, 2001, p. 1) Dr. Cartwright was so helpful as to identify preventive measures for dealing with potential cases of drapetomania. Slaves showing incipient drapetomania, reflected in sulky and dissatisfied behavior should be whipped—strictly as a therapeutic early intervention. Planter and overseers were encouraged to utilize whipping as the primary intervention once the disease had progressed to the stage of actually running away. Overall, Cartwright suggested that Negroes should be kept in a submissive state and treated like children, with "care, kindness, attention and humanity, to prevent and cure them from running away." (Cartwright, 2001, p. 1)

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Dr. Cartwright also diagnosed *Dysaethesia Aethiopica,* or "hebetude of the mind and obtuse sensibility of the body— a disease peculiar to Negroes called by overseers—Rascality." (Cartwright, 2001, p. 2) Dysethesia Aethiopica differed from other species of mental disease since physical signs and lesions accompanied it. The ever-resourceful Dr. Cartwright determined that whipping could also cure this disorder. Of course, one wonders if the whipping were not the cause of the "lesions" that confirmed the diagnosis. Not surprisingly, Dr. Cartwright was a leading thinker in the pro-slavery movement. Dr. Cartwright, in his article "Diseases and Peculiarities of the Negro Race," chided his anti-slavery colleagues by noting "The northern physicians and people have noticed the symptoms, but not the disease from which they spring. They ignorantly attribute the symptoms to the debasing influence of slavery on the mind without considering that those who have never been in slavery, or their fathers before them, are the most afflicted, and the latest from the slave-holding south the least. The disease is the natural offspring of Negro liberty—the liberty to be idle, to wallow in filth, and to indulge in improper food and drinks." (Cartwright, 2001, p. 3)

Drapetomania and Dysethesia Aethiopica could be relegated to obscurity along with the spinning chair and other ridiculous assumptions about mental illness and its treatment if African-Americans were not constantly assaulted by updated efforts to put social and economic issues into a medical framework that emphasizes our "pathology." In the late 1960s, Vernon Mark, William Sweet and Frank Ervin suggested that urban violence, which most African-Americans perceived as a reaction to oppression, poverty and state-sponsored economic and physical violence against us, was actually due to "brain dysfunction," and recommended the use of psychosurgery to prevent outbreaks of violence (Mason, 1973). Clearly, the spirit of Dr. Cartwright was alive, well and receiving federal research grants. Drs. Alvin Poussaint and Peter Breggin were two outspoken opponents of the updated "Drapetomania" theory, along with hundreds of psychiatric survivors who took to the streets to protest psychosurgery abuses. The issue of brain dysfunction as a cause of poor social conditions in African-American and Latino communities continues to crop up in the federally funded Violence Initiatives of the 1990s (Breggin, 1998) and current calls for psychiatric screening for all children entering juvenile justice facilities. Exposing scientific racism is essential to protecting us from further psychiatric abuses and facilitating resolution of social, political and economic problems without blaming the victims of oppression.

In 1895, Dr. T. O. Powell, Superintendent of the Georgia Lunatic Asylum, reported an alarming increase in insanity and consumption among Negroes in Georgia. Dr. Powell noted that these conditions were virtually unheard of among Negroes up to 1860. A comparison of census records between 1860 and 1890 showed that insanity among Negroes had increased from one in 10,584 to one in 943. Dr. Powell believed that the

hygienic and structured lives led by slaves served as protective factors against consumption and insanity. According to Dr. Powell, "Freedom, however, removed all hygienic restraints, and they were no longer obedient to the inexorable laws of health, plunging into all sort of excesses and vices, leading irregular lives, and having apparently little or no control over their appetites and passions." (Powell, 1895, p. 5) To sum it up, freedom made us nuts. Apparently, Powell failed to factor abject poverty, further disruption of family and kinship ties, racism, and terrorism into the high rates of insanity.

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The 1840 census revealed dramatically increased rates of insanity among free blacks. African-American physician James McCune Smith challenged the findings of 1840 census, which was frequently used by pro-slavery writers to confirm that enslavement was beneficial to slaves. Dr. Smith wrote, "Freedom has not made us 'mad.' It has strengthened our minds by throwing us upon our own resources." (Gamwell and Tomes, 1995, p. 102).

What role did the need for cheap labor to staff psychiatric hospitals play in the incarceration of former slaves? The Georgia Lunatic Asylum, which would come to be known as the largest lunatic asylum in the word, was operated exclusively by slave labor from 1841–1847, when the first white attendants were hired (Cranford, 1998). The slave attendants and help-patients were a critical adjunct to hospital staff. Other factors that may have influenced the rates of insanity following the Civil War were starvation and poor nutrition, which led to pellagra, a niacin deficiency with symptoms of loss of appetite, irritability and mental confusion. This disease disproportionately affected poor and displaced former slaves.

The Colored Hospital

African-Americans were frequently housed in public (as opposed to private) facilities such as the poorhouse, jail or the insane asylum. These facilities almost always had substandard conditions. If conditions in the facility were poor for white patients, conditions were completely inhumane for African-American patients. For instance, one of the first patients admitted to the South Carolina Lunatic Asylum in 1829 was a fourteen-year-old slave named Jefferson. Jefferson's name was not recorded in the admission book and he was reportedly housed in the yard. The young slave was admitted as a favor to his owner since the facility did not officially receive blacks (McCandless, 1996, p. 76).

The issue of housing Black and white mental patients in the same facility was a struggle in both Northern and Southern States since many leading mental health experts felt that it undermined the mental health of white patients to be housed with African-Americans. The distress of having Blacks and white patients in close proximity to one another was balanced by the unwillingness to fund segregated facilities for black patients.

In March 1875, the North Carolina General Assembly appropriated $10,000 to build a colored insane asylum (Powell, 1879). The Eastern Asylum for the Colored Insane was opened in 1880 with accommodations for four hundred and twenty patients. The facility at Goldsboro underwent several name changes throughout its history and remains in operation as a psychiatric facility. In 1925, Junius Wilson, a seventeen-year-old, deaf and mute black man was accused of rape, castrated and remanded for incarceration at Goldsboro by a "lunacy jury." The rape charges were eventually dropped in the 1970s and at some point authorities realized that Mr. Wilson was neither mentally ill nor retarded—simply hearing impaired. In 1994, at the age of 86,

Mr. Wilson was moved to a cottage on the grounds of the facility (now known as the Cherry Hospital). The move to the cottage was the state's effort to make up for Mr. Wilson's 72-year incarceration. He died there in March of 2001. (The Charlotte *Observer*, March 21, 2001).

Virginia established an asylum for the "colored insane" in Petersburg that received its first patients in April 1885. At that time there were approximately four hundred "insane Negroes" in the state, all of whom were cared for in the Petersburg facility (Powell, 1879, p. 16). Apparently little concern was given to the ability of family and friends throughout the state to visit their loved ones at the facility that was so far from home for so many.

The Alabama Insane Hospital was not for the exclusive use of African-Americans, but to accommodate the increasing number of African-American patients, separate facilities were created on the grounds. In 1897, Dr. T.O. Powell reported that the Alabama facility had about three hundred and fifty African-American patients. The facility maintained a "colony" of one hundred African-American men about two miles from the main facility. Dr. Powell noted, "They are contented, are the healthiest class of patients under this management and by their farm labor contribute to the support of the institution." (Powell, 1879, p. 41) It is interesting to note that the positive presentation of the "colony farm" obscures the reality that the primary "treatment"

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provided to these African-American male patients was hard physical labor. It seems odd that individuals who had been incarcerated in an asylum due to their insanity were able perform tasks that must have required some degree of skill and focus.

Dr. James Lawrence Thompson, in his memoir of life at the South Carolina State Hospital, noted "It was customary to employ as many of the patients as possible—those who were in condition to work—both male and female, white and colored. The white females would make beds, sweep the floors, sew, work in the kitchen and even sweep the yards. The colored females would work on the wards in various ways and in the laundry. The colored males did most of the rough work, such as working on the farm, cutting wood and the like. The white males were somewhat handicapped in their work as it was not customary to have the white and colored males working together and we did not have land enough to have the white males work on the farm, hence they were confined to work mostly in cleaning up the yards and moving trash from about the building." (Thompson, 1934, p. 7) Perhaps patients, both African-American and white, could have benefited more from the restorative power of gainful employment provided in their own communities and with adequate financial compensation.

The state of Maryland opened its hospital for the colored insane in 1911 near Crownsville, MD. The first patients were composed of 12 patients from the Spring Grove facility and 112 inmates from jails or other asylums. The inmates, who lived in a temporary camp while they began to clear the land and operate the farm, built the facility. It was noted that Dr. Robert Winterode decided to "entrust" the patients with axes and tools to complete the construction. Prior to the opening of the Crownsville facility, African-American patients were housed in segregated facilities on other facilities and in local jails. At the turn of the century, African-American males at Maryland's Spring Grove facility often spent up to eight months living in tents, made with patient labor, on the grounds. A cottage for African-American females was completed at Spring Grove in 1906. (Spring Grove on-line reference)

In 1919, Rusk State Penitentiary in Texas was turned into a hospital for the "Negro insane." The facility

achieved notoriety when, on April 16, 1955, a group of African-American prisoners in the maximum-security unit rebelled and took over the hospital for five hours. The rebellion was led by nineteen-year-old Ben Riley, who articulated inmate demands for better counseling, organized exercise periods, an end to prisoner beatings, and that all inmates have the same rights enjoyed by the white inmates regarding meals, bathing and freedom of movement. (Texas Rangers on-line reference) The article in the Austin *Statesman* reflects the power of having control of the media: it stated that the prisoners had "no specific complaints," and described Ben Riley as the "leader of the gang of criminally insane Negroes" and as someone who "likes to exhibit his muscles." (Lloyd, 1955) Readers get the sense that the reporter was barely restraining himself from calling the young leader a "big Black buck." The Austin *Statesman's* article is accompanied by a photo of a shirtless Riley with a caption that notes that the man was pointing to scars on another inmate that were reportedly caused by a beating. Is it possible that Riley was not just taking the opportunity to "exhibit his body" but was showing his own scars?

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During the siege, the inmates reportedly hooked the hospital superintendent up to the electroshock machine and attempted to deliver maximum voltage to him. The superintendent escaped injury when the inmates pushed the right button but failed to set the spring correctly. (Sitton, 1999, p. 112) In her well researched book on the Texas State Lunatic Asylum, it is notable that author Sarah Sitton fails to note that Rusk State Hospital was established to serve African-American patients. Sitton is very sympathetic to the plight of attendants dealing with threats of violence *from* African-American prisoners but shows little concern for the violence perpetrated *against* African-American inmates.

This section is not intended to imply that the only place where African-Americans experienced the psychiatric system was within facilities. The history of institutional-based treatment is simply better documented than other interventions provided to—or abuses perpetrated against—African-American psychiatric survivors. There is a rich history regarding natural healing and spirituality that needs further exploration to fully understand the efforts used in the community to honor and heal mental illness and trauma reactions.

African-American Resistance to Psychiatric Oppression

Ben Riley's rebellion was not an isolated instance of resistance to psychiatric abuse. I was appalled by the all-white panel assembled for the 2000 Alternatives Conference, a psychiatric survivor empowerment conference, to discuss the history of the psychiatric liberation movement. Had people of color been patiently waiting for their white brothers and sisters to liberate them? Or had we once again been left out of the official record?

Luisah Teish is an African-American activist, priestess, psychiatric survivor and author who co-edited the *1976 Third World Issue of Madness Network News*. The special issue included Teish's article, "That Nigger's Crazy," which highlighted scientific racism from Samuel Cartwright to Shockley and Jenson. She notes, "We know that if sanity is defined by white upper-middle class standards then we are in grave danger. It is very easy at this time, when Third World people are seeking our own identities, to say, 'That Nigger's Crazy… LOCK HIM UP!' " (Teish, *Madness Network News*).

In her book *Jambalaya,* Ms. Teish reflects on an incident in which she loses all hope and literally drifts out of her body:

> *I call this experience my nervous breakthrough. Prior to it, I was literally out of my mind. For a month I was quiet as a church mouse all day, and I screamed all night that I was captive on this planet and did not want to be here. I was strung out on doctor-prescribed dope and poison and under the influence of people who themselves were frightened and powerless. Like many others, I made the mistake of judging my worth by the paper in my pocket and arrogantly rejected the beauty of the flowers.*
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> *I wanted to be an asset to my community, to contemplate the meaning of existence and produce beauty. But literally everything in the society told me I was a useless nigger wench. I was someone who was best forgotten and destined to be destroyed. I was caught between my soul's desires and society's dictates.*
>
> *Thank Goddess, my sister, Safi, was confident that I would come through it, so she did not call for 'the man' in the white coats.*
>
> *Since then I have worked as a mental patient's advocate, and I maintain that many people in our state institutions are really in spiritual crises. The addition of mind-melting drugs makes their breakdown almost inevitable.* (Teish, 1985, pp. 39–40).

Ms. Teish offers a political and spiritual analysis on mental illness that is rarely considered within clinical settings. She offers a re-connection with traditional healing practices to help us turn the medical "nervous breakdown" into a spiritual and political "nervous breakthrough".

The plight of African-American males in the psychiatric system is vividly captured in *Hurry Tomorrow,* a shocking documentary of conditions at Metropolitan Hospital in Norwalk, California. (Cohen and Rafferty, 1975) In one scene, an assertive, young African-American male is trying to explain to an all-white clinical team his reality as a poor, Black man. He is mocked by the psychiatrist and lined up for Thorazine injections. Later in the film we see him shuffling through the cafeteria line barely able to hold his tray due to over-medication. It is a chilling scene of the suppression of the activist voice and it is done away from public view and protected by confidentiality laws that serve to protect mental health providers more than it ever protected survivors.

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—Luisah Teish

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The official record ignores the activism of Goldie Marks of Toccoa, Georgia, past president of the Georgia Mental Health Consumer Network, who continues to advocate for herself and other mental health consumers. In her oral history interview, Ms. Marks recounts her attempt to elude her counselor and the police to avoid involuntary hospitalization following a statement of despair that was misinterpreted as a suicidal threat. She shared her story of surviving nine months in Central State Hospital and her continuing fight to secure her medical records related to that hospitalization. (G. Marks, personal communication, 8/23/2000) Ms. Marks worked with other Georgia consumer/survivors to secure restoration of the patient cemetery in Milledgeville, Georgia, and was present when a representative from Georgia's Division of Mental Health/ Mental Retardation/Substance Abuse made a public apology to consumer/survivors for the desecration of patient graves and the abuse and neglect of patients by the state system. There is still much work to do in

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the psychiatric liberation struggle but we have our day-to-day heroes who have been and continue to be committed to the cause.

Leadership in a movement is all too often defined by who is sitting on the dais or has the ear of the rich and powerful. There were thousands of African-American activists who resisted psychiatric oppression on a daily basis, but many of them are lost to us because they are not recorded in the official history. We can no longer wait for the predominately white c/s/x movement to include us as an addendum to their history. We will have to write our own history to celebrate our legacy of resistance.

Chapter II: Truth Telling: Giving Voice to Liberation

"It is important that black people talk to one another; that we talk with friends and allies, for the telling of our stories enables us to name our pain, our suffering and to seek healing."

bell hooks
Sisters of the Yam

Social critic bell hooks is an outspoken advocate of the need for African-Americans to engage in psychological healing to address the legacy of slavery and the ongoing traumas related to being marginalized in American society. She recognizes that the connections that we can make with each other and the repeated telling of our truths are forms of emotional healing. The collection of oral history puts the power to heal in all of our hands.

The initial phase of the *In Our Own Voice* project included interviews with twelve African-American psychiatric survivors. The interviewees ranged in age from thirty-three to seventy-five years of age. Four of the interviewees were male and seven were female. The majority of interviewees were raised in poor or working class backgrounds but three interviewees were raised in middle-class households. Two of the interviewees identify as gay or lesbian. Five of the female interviewees identified as sexual abuse survivors. The interviewees lived in geographically diverse areas. The interview format was unstructured and people were invited to just talk about their lives and how their experience with being labeled mentally ill had affected them. In spite of the limited number of interviews collected in this phase of the project, it was important for us to ensure that the interview pool reflected as much of the diversity of the African-American community as possible. It was especially important to ensure that the experiences of members of the gay/lesbian/bisexual/transgendered were incorporated into the project. The double minority status of gay/lesbian/bisexual/transgendered individuals and the "Play it but don't say it" homophobic attitude in the African-American community makes for an additional layer of trauma for this group of psychiatric survivors.

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The oral history project provides a unique opportunity for dialogue among the African-American psychiatric survivors and the wider community regarding the intersection of racism, classism, sexism, ageism, mentalism, and heterosexism. We may be in a unique position to offer guidance to the wider African-American community regarding the deep and traumatic impact of oppression on our psyches. It is been my experience that psychiatric survivors have a greater ability to talk openly about our lives. This may be a by-product of the involuntary sharing in coercive therapy, the openness created through genuine therapeutic interactions or simply the relief, after frequent exposure to active ignoring in treatment facilities, at being able to tell our stories. The following excerpts were selected because they capture the experience of mental illness and oppression across several decades with interviewees who have been involved in the mental health system for over thirty years. The interview with Ms. Clemons also allows African-American survivors a rare glimpse into the legacy of trauma and mental illness left in the wake of racist oppression and the struggle for civil rights.

Pearl Johnson

At age 70, Pearl Johnson is a leading African-American psychiatric survivor activist. She was born in Hollywood, Louisiana, a small town outside of Shreveport. Ms. Johnson described her childhood as being wealthy because there was a garden with plenty of food but oil stoves and no running water. She described her early experience with sexual molestation, physical violence and emotional harshness. It is with a different tone that she describes her "jack rabbit" spirit that made her an excellent athlete and potential Olympic runner. She described the culmination of parental pain and confusion that landed her in state custody at the age of sixteen labeled an out of control child. The irony of the situation was that this was a child who was focused on sports and athletic success. Once she found herself incarcerated in a juvenile facility in California, Pearl used those athletic skills to liberate herself and make her way to New York State. She was eventually arrested on "white slavery" charges because a thirteen-year-old girl joined her in the breakout and they had moved across the country together. At sixteen, Ms. Johnson had her first encounter with the mental health system. Due to her constant crying she was labeled with depression. She eventually returned home to California and the maternal violence resumed. This excerpt of the interview picks up where Ms. Johnson makes her decision to leave home for good at age seventeen.

Ms. Johnson: I came back to California and started going through all of the same stuff. You look just like your no good daddy and this and that. Getting beat….

Interviewer: By your mother…? Or by…?

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> The most painful part of Ms. Johnson's story is that in all of her mental health treatment, the issue of sexual and physical trauma has never been addressed.
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Ms. Johnson: By my mother. And the last time she hit me she had grabbed me like this…by my nose…and had a double-barrel shotgun and I hadn't done nothing.

Interviewer: How old were you, Pearl?

Ms. Johnson: Seventeen…. So I ran…I really ran that time. I ran 'til I wound up in jails, hospitals, and institutions. I ran 'til I started sleeping with a man and got pregnant…. I ran 'til I started drinking wine. I ran 'til I got to become a thief. I just ran. And I didn't stop running for fifty-one years. Until here lately. My life has been real, real, real, real, real rough. I don't know if I had shock treatments or not 'cause I went into a state of shock. In nineteen and fifty-three, I was arrested…I didn't know what for. They gave me twelve years in the state penitentiary. I…I…I still don't know…. Why so much time and I didn't have nothing on me? …Oh, lord…. [tearful]

Interviewer: It's okay…just take your time…take your time, Pearl.

Ms. Johnson: A lot of that stuff that I seen today brought a lot of that back. [reference to c/s/x consumer history slide presentation viewed prior to interview] One time I woke up and I did not have top teeth. I had top teeth but they were all broke up. I don't know if it was from shock treatments or from me gritting or whatever. But anyway, they had to pull all of my teeth out. Uhm… I've been a dope fiend….

Interviewer: What did you use?

Ms. Johnson: I used heroin…uhm…morphine…. Morphine was the real deal in those days. I had

sense enough to not use it with my children…when I was pregnant…. But all of the rest of the time…. My children were taken from me.

Interviewer: How many children do you have?

Ms. Johnson: I had three. My oldest son was… My daughter just told me…. I blocked all of that out. He got beat to death. Uh…he had things with his mind…. He had suicidal tendencies. Uh, he got beat to death…he got beat with a lead pipe…and I watched him die for twenty-eight days. Let's say it that way.

Ms. Johnson recounted several near death experiences and the suicide of several friends when she was incarcerated. She was homeless during much of the fifty-one years she spent running. The most painful part of Ms. Johnson's story is that in all of her mental health treatment, the issue of sexual and physical trauma has never been addressed. She has been labeled with clinical depression and most recently with Schizophrenia, Paranoid Type. Ms. Johnson's story is ultimately a story of survival and commitment to supporting recovery that is hard to match. At the age of seventy, Ms. Johnson described herself as "just finding myself."

Ola Mae Clemons

Ola Mae Clemons is a quiet, dignified woman who lives in an apartment on a quiet street in Albany, Georgia. In 1963 at the age of nineteen, Ola Mae Quarterman refused to sit on the back of the bus in that same town, and spent the next thirty days in jail. As she says, "I paid my damn dime…. I can sit where I want." She is known as the "Rosa Parks of Albany." A dedicated civil rights activist, she spent the next two years involved in civil rights organizing. She was expelled from Albany State University for her participation in civil rights activism. In 1965, following a troubled marriage and the birth of her child, she experienced what she described as a "nervous breakdown." At the age of twenty-one, Ms. Clemons ended up in Central State Hospital in Milledgeville, Georgia, were she remained for thirty-five years. It is notable that her extended stay occurred during a period of massive deinstitutionalization, yet this quiet, nonviolent woman remained at the facility. She missed out on raising her child, enjoying the changes that her activism created and the opportunity to maintain connections with her activist friends. Ms. Clemons reports that she had nearly one hundred shock treatments during her stay at the hospital. When asked about her time at Central State Hospital, Ms. Clemons described her time there as "exciting times" since she was a "volunteer" [voluntary] patient and had ground privileges. Since her release from the hospital in 1998, she participates in day treatment and case management services and is frequently interviewed by the press regarding her civil rights history.

Interviewer: Kind of going back, one of the things I'm trying to understand, especially about the African-American experience…. I hear a lot of different stories and everyone has their own experience, but as far as you know—in terms of your treatment—you said that you did not get shock…electric shock treatment…at all?

Ms. Clemons: I did.

Interviewer: You did?

Ms. Clemons: I probably have taken more shock treatments than anybody else has ever had.

Interviewer: How…. Do you know how many?

Ms. Clemons: I think it's about ninety-something shock treatments. Or a hundred.

Interviewer: Wow. What do you remember about getting shock treatment?

Ms. Clemons: Well, I took mine knock out…. I took mine without medicine.

Interviewer: So you took yours with medicine or without….

Ms. Clemons: Without.

Interviewer: So you were awake?

Ms. Clemons: Right. And they knocked me out with the electricity.

Interviewer: And what do you remember after you woke up.

Ms. Clemons: Nothing. But when I went to get up and it knocked me unconscious.

Interviewer: Did it help?

Ms. Clemons: It did help…help for a while. It makes you have an appetite. It makes you relax. It makes you forget all the problems you had. Your mind goes blank. But I would rather not take it because when my mind come back to it, I can remember my class work, my books I read. My homework…my church, my minister. But when you taken those you forget a lot of things.

Interviewer: So you lost some of your history taking the treatments.

Ms. Clemons: Right.

Interviewer: I hear a lot of that. It sounds like what you were experiencing was depression.

Ms. Clemons: Self-depression?

Interviewer: Is that what…. Do you know what your diagnosis is at all?

Ms. Clemons: Schizophrenia. Paranoid schizophrenia.

Interviewer: Okay. Hmm…. Because what you described sounds a lot like someone who's just really sad.

Ms. Clemons: [Laughter] It's sad. I hope I don't have to go through that again.

Interviewer: Did you…?

Ms. Clemons: Because next time I am marching with the whites. [laughter]

Interviewer: What?

Ms. Clemons: The whites gonna have to march…. [laughter]

Interviewer: Your not going to do it by yourself this time, that's what you're saying?

Ms. Clemons: Right! I'm going to obey and be humble. [laughter]

Interviewer: You think you would be? If you really had it to do over again, would you be humble?

Ms. Clemons: I would. I sure would.

Interviewer: Where do you think we would be as a people?

Ms. Clemons: Where do I think we would be as a people?

Interviewer: Yeah.

Ms. Clemons: [unintelligible]

Interviewer: As Black people especially.

Ms. Clemons: I think we would hug up with the whites. [laughter]

At the end of the interview, Ms. Clemons makes the heart-breaking comment, "I guess I was the only one that cracked up." This statement highlights the danger of failing to look at context, especially the political and economic context of an individual's life before they are labeled with mental illness. In my judgment, Ms. Clemons was a political prisoner, and her thirty-five years of incarceration in Central State Hospital had more to do with her agitating for social justice than it ever had to do with schizophrenia. She is a survivor in the truest sense of the word. How would her life have been different if she had been able to participate in the "soul sessions" that Alvin Poussaint, MD, and others created for civil rights activists to process the hatred and violence they were experiencing daily? (Poussaint personal interview). What if the civil rights leaders had been less fearful of embracing the wounded leaders and workers and had not rendered these individuals invisible within the movement? This was post-traumatic stress disorder without the benefit of the "post," since the violence and threat of violence was constant and unyielding. It speaks to me of the evil of our political system, and the psychiatric system that often functions as its handmaiden, that at no point in her treatment was the issue of her harassment, abuse, and incarceration addressed as an act of racism and repression for her activism. Instead she is left feeling that if she had to do it over again she would "sit where the man told me to sit."

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Quincy Boykin

Quincy Boykin is a fifty-six-year-old African-American male from New York City who is a mental health survivor activist. In his interview, Mr. Boykin described the impact of a one-year tour of duty in Vietnam in 1965–66 and the drug use and depression that followed upon his return to his family. His story highlights the unique challenges faced by African-American males within the mental health system and American society. How does American society's lack of permission for men, especially African-American men, to express feelings of sadness, helplessness and loss, contribute to the mental distress in men daily confronted with oppression and pain? Mr. Boykin's first contact with the mental health system was at the age of forty-six when he was picked up on the street and held in a psychiatric ward for three months. He recounts his anger at the friend who arranged for his extended incarceration until a community-based placement could be found for him. Mr. Boykin described the hospitalization and the after-care as a significant turning point that broke the

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cycle of twenty years of heroin abuse. He raised important questions about the misdiagnosis of African-Americans, especially males with substance abuse and trauma backgrounds, as having schizophrenia and embarking on often debilitating and useless treatment. Mr. Boykin also raised crucial questions regarding the silence and shunning of individuals with mental illness within African-American families—even families that are otherwise loving and supportive. He speaks with pride about maintaining his relationship with his own children in spite of his drug abuse and trauma and makes visible the reality of survivors as parents, husbands, children and activist. In his interview, Mr. Boykin talks about the impact of his civil rights activism in the late sixties and the cultural depression of lost dreams. His story provides a rare glimpse into the trauma created by a crushed and compromised revolution for black liberation and wide-scale societal transformation. (Boykin, personal communication, 11/22/2000)

In Our Own Voice is a small beginning and we cannot possibly convey all of the rich voices of the interviewees in this resource guide. However, some themes were identified through the interviews that are in need of further exploration and elaboration.

Spirituality

The majority of the interviewees spoke of the importance of their spirituality in their recovery process. One interviewee identified as Muslim, and the rest identified with some form of Christianity. My own spiritual tradition incorporates African ancestor worship and is heavily influenced by the work of psychiatric liberation activist, priestess and author Luisah Teish. At the worst moment of my depression, I created an altar to reflect my intense pain and my hope for recovery.

Several people talked about the need to help religious institutions respond more effectively to mental health concerns. An interviewee who identifies as a lesbian recalls being subjected to a form of "exorcism" as a child to deal with perceived mental health issues and the sense for her family that "if you don't fix this now, you are going to have a lesbian on your hands." The depth of spiritual wounding that can occur when an individual is cut off from his or her religious community or, even worse, when religion is used to further abuse people, is incredible. On the other hand, the power that spirituality has to heal and to restore a survivor's sense of self and serve as a vehicle for reconnection to community is equally powerful. The documentary *Dakar: When the Spirits Are Angry* chronicles a healing ritual in Dakar, Senegal, during which a woman suffering from diabetes and emotional distress is treated by the local healer. There were many amazing events that occurred in the course of this nearly week-long ritual, but what stood out for me most was that the entire community was involved in lending energy, through music, dance, cooking, prayer, to this woman's recovery. Maybe community connection was the key to her healing. A local doctor noted, "The ritual is designed to cure the sick person and the community, which believes that [he or she] is sick." (Dakar, 1999) The understanding that the community must be healed for the person to truly be well is a radical notion that would be useful for modern psychiatry to consider. How can we draw on these traditions to create a model of recovery for African-American psychiatric survivors?

Family

A constant theme throughout the tapes was the challenge of remaining visible as psychiatric survivors in our family systems. Many interviewees talked about the estrangement from their families due to embarrassment and shame about their mental health diagnosis. One interviewee talked about her desire to use her tape to initiate a discussion about mental illness in her family. Even in extremely supportive families there was a willingness to talk about anything but the mental illness. Families were able to have weekly visits or phone calls to loved ones in the hospital yet still not acknowledge the mental illness. The majority of the interviewees who address this issue directly seemed to accept invisibility as something they had live with to maintain a connection with their families.

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A seventy-five-year-old African-American woman from the northeast talked about her challenge in dealing with her mental illness in the face of her husband's controlling behavior. Although her husband was financially—and to large degree emotionally—supportive of her, his own confusion and shame about mental illness may have prevented him from allowing his wife to find her own path of recovery. She noted that she resisted his demands that she should not take medication and began her recovery process. This interviewee also spoke of the value of her "work family," which assisted her in maintaining employment and independence as she struggled to deal with her mental illness.

Social Activism

The majority of interviewees were involved in some type of advocacy work related to psychiatric recovery or other anti-oppression activities. Quincy Boykin and Pearl Johnson all spoke passionately about the value of their activism as a recovery tool. Mr. Boykin and several other interviewees noted that they were raised in politically active families or were engaged in social activism prior to their experience with a psychiatric diagnosis. Ola Mae Clemons's story reminds us of the cost of social activisms and the need for us to view the good health of our spirits and minds as tools for social change as well. Readers are encouraged to read *Sisters of the Yam: All About Love* and *Salvation: Black People and Love* by African-American feminist cultural critic bell hooks, for more discussion regarding the therapy and emotional health as revolutionary acts in the African-American Community.

Oppression in all its Faces

The issue of oppression was a constant theme throughout the interviews, including class oppression and its impact on the manifestation and treatment of mental illness. Sexism was an issue for males and females because it contributed to the normalization of the sexual victimization of female survivors and served as a barrier to males openly expressing their pain and distress. Heterosexism played out in the labeling and forced treatment of individuals identified as gay and lesbian and the invisibility within the African-American community of our gay/lesbian/bisexual/transgendered (GLBT) brothers and sisters. A lesbian psychiatric survivor described her experience as a small child being subjected to an "exorcism" since her parents had been informed that they would "have a lesbian on their hands" if they did not intervene immediately. When religious intervention failed, the family resorted to the psychiatric system for assistance and initiated a four-decade-long process of

psychiatric oppression. I felt proud when the newly forming national organization of African-American psychiatric survivors acknowledged the need to specifically identify our support of our GLBT brothers and sisters in our statement of purpose. I hope that we can avoid the pitfalls of so many liberation movements by embracing and celebrating all African-American survivors.

A more detailed exploration of the experiences of African-American youth and elders is needed and those voices really need to be amplified because of the tendency to focus on the people most likely to be at the decision making table—those between twenty-one and sixty. I believe that the African-American psychiatric survivor movement is in unique position to explore the intersections of these various forms of oppression and use this knowledge to strengthen our movement and our communities.

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Violence

The issue of violence, in various forms, is rarely discussed except to address the violence perpetrated *by* individuals diagnosed with mental illness. Significant themes within the interviews were physical, sexual and emotional violence which were rarely, if ever, addressed within the clinical environment. The clarity with which Pearl Johnson speaks of the violence that she experienced throughout her life makes it all the more shocking that a therapist never followed this theme as a source of her depression and substance abuse; it amounts to nothing less than malpractice. The larger issue of cultural violence in the form of the suppression and violation of our civil rights is also ignored in psychiatric literature but is an ever-present reality in our daily lives. How do we address these issues while avoiding yet another psychiatric label? If an entire group experiences symptoms of post-traumatic stress disorder, when does it shift from being an individualized psychiatric disorder to a public health crisis that must be addressed at its root?

Chapter III: Honoring Our Past, Celebrating Our Present and Protecting Our Future

The value of historical preservation and oral history collection should be clear to everyone. However, it is politically and economically challenging to advocate for public funding for history projects at a time when mental health prevention, clinical and residential programs are under-funded. Do we make history collection a higher priority than agitating for the repeal of oppressive commitment and forced medication laws? Do we even want to preserve such a horrible history of psychiatric abuses? If you had asked me my thoughts a year ago, I probably would have quoted Mother Jones: "Pray for the dead and fight like hell for the living." But the past year has changed me from a mental health user/social worker into an amateur historian. More importantly, it has radicalized me, made me briefly question whether there was a way to function ethically as a therapist (there is; many of the interviewees identified supportive clinicians who stood by them through their recovery), and connected me to my own history. This issue is not whether a history is worth preserving but who is in charge of the preservation effort. It is exciting to see the national movement to restore cemeteries and collect survivor oral history. As African-Americans, we have to be involved in these historic preservation efforts. A recent article in the Columbia, South Carolina, *Free Times* described the plan to construct a driving range over the graves of as many as nineteen hundred African-American mental patients in Columbia, South Carolina. The World Golf Foundation and the Tiger Woods Foundation's First Tee program is designed to provide children and communities access to golf who would otherwise would have little or no exposure to the sport. The article quoted a seventy-two-year-old neighbor in the adjacent African-American neighborhood as commenting, "I don't see what the fuss is all about. It cleans up an area in our neighborhood that has needed to be cleaned up since I was a child." (Cato, 2001) It is especially destructive to African-Americans to have our past pitted against our future or for economic development to come at the cost of a loss of human dignity and reverence for our ancestors.

As African-American people we do not have the luxury of being forgetful or ignorant of our history. We have lost much, contributed even more and survived against all odds during our sojourn in American. We now have an opportunity to reclaim some of the lost parts of our history and ourselves. As psychiatric survivors we have a unique opportunity to heal ourselves while offering a model of authentic healing to our community. We are *griots* and the telling of individual stories opens the door to reclaiming the truths about our communities and our collective experience.

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Through my work on this monograph, I learned many valuable lessons that I will share with other amateur historians in the hope that you will avoid some of my missteps. However, we each will have to find a way to reclaim our history based on the resources that we have available to use. The beauty of historical research is that it need not cost much if anything. The *In Our Own Voices* project consisted of background research, which included a literature review, a more thorough review of several key books that are listed in the resource section and a review of original documents at Central State Hospital in Milledgeville, Georgia. The trip to Milledgeville was especially valuable to me because it helped me to connect with the spirit of a place dedicated to the incarceration of the socially undesirable. It allowed me a chance

to have conversations with African-American former staff members that were not recorded in the official record. One of the more cynical observations I made during my visits to Milledgeville was that all of the African-American wards that are still standing have been turned into prisons.

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The most important lesson I learned during my research was to start with the oral history collection to help ground the researcher in the importance and validity of the individual voice. I will add that the first oral history that should be collected should be your own story. I taped my story about midway through the process and I was humbled by the difficulty of listening to my own tape. I had told the story of my depression and the related story of my sister's suicide in a number of settings but I was amazed at the power of sitting down for forty-five minutes and telling my story uninterrupted into a tape recorder.

Interview format

There are many strategies for collecting stories from individuals and each interviewer will develop his or her unique style through trial and error with various interviewees. I highly recommend unstructured interviews with minimal guidance other than to ask people to talk about their experiences with mental illness/mental illness label. The interviewer should make it clear at the beginning if there are any time limitations so that the interviewee can pace him/herself within the allotted time. When possible, I encourage follow-up interviews to allow for deeper exploration and clarification of certain aspects of the story.

Pat Deegan, a psychiatric survivor/activist with a Ph.D. in clinical psychology, notes that it is important to let the stories unfold because the stories of our experiences as psychiatric consumers/survivors/ex-patients are frequently trauma stories. (P. Deegan, personal communication, 7/8/2000) Trauma stories tend to unfold in layers with frequent doubling-back to re-connect with another aspect of the personal history. Do not expect the telling of a psychiatric story to emerge in a straightforward, linear fashion. Always honor the feelings that come up, and inform interviewees at the beginning of taping that they are free to pause or terminate the interview at any time. It should be clear that the interviewee is in control of his or her historical material during the interview and in the future use of the oral history tapes.

If the interviewer prefers a more structured interview format, I can offer a few suggestions regarding introductory questions. The key to any interview is to be flexible and follow the lead of the interviewee. I have used some of the following questions during structured oral history interviews:

1. What is one thing that you love about yourself?

2. When were you first diagnosed with a mental illness? What were the circumstances of your diagnosis?

3. What experiences stand out most for you related to being labeled mentally ill?

4. What was your most positive experience with the mental health system?

5. What was your most negative experience with the mental health system?

6. How did /does your family and friends respond to your emotional crisis?

7. What helps you to heal? Have you ever used nontraditional (nonmedical model) interventions to support your recovery?

8. What, if any, impact did being African-American have on the manifestation of behaviors labeled as mental illness or your treatment?

9. Knowing what you know now, what would you do differently about your contact with the mental health system?

10. What do you feel is important for African-Americans to know about mental illness, treatment and recovery?

A brief but powerful series of questions was offered by Pemina Yellowbird, author of *Wild Indians: The Untold Story of the Canton Asylum for Insane Indians.* (P. Yellowbird, personal communication, 7/8/2000) As she and I discussed our respective history projects and ways to honor traditional methods of healing, Pemina noted that healers in her tradition offer three core questions:

1. What happened to you?

2. How does what happened to you affect you now?

3. What do you need to heal?

Aside from the value of these questions in eliciting oral history, imagine the healing power of these words if they were a routine part of a mental health interview.

I encourage individuals and groups working on oral history projects to experiment with a variety of questions to see which ones facilitate the sharing of stories without re-traumatizing individuals. At the end of an interview it is always important to debrief the interviewee and talk a little bit about how it felt to be interviewed. I always offer interviewees the option of contacting me for further debriefing if they find that they continue to be troubled by the material discussed in the interview. It has been my experience that interviewees feel a sense of relief and validation at the end of an interview. Several interviewees noted that it gave them a chance to look at their experience from a different perspective. I provided all of the interviewees with a copy of their tapes to review prior to signing a release of information.

Payment for interviews

The issue of payment for interviews is a financial and ethical decision. The interviews conducted as part of this project were voluntary and offered without financial compensation. However, many oral history projects do provide a small stipend to compensate interviewees for their time. There is no way to adequately compensate someone for his or her story and compensation in no way implies ownership of the final product. I believe that interviewees should be fully informed regarding the possible use of their tape and sign a written consent form outlining how the tape and transcript may be used in the future.

Voices of Allies in the Struggle

I encountered a challenge at the very beginning of this project when I had the opportunity to interview an African-American man who had worked at Central State Hospital from 1932 to 1972. J.C. Hogan shared his story of witnessing the oppression of African-American patients and staff, his efforts to create a humane environment for the one hundred African-American children on the ward where he worked, and the desegregation of the hospital in 1965. (Hogan, personal communication, 6/22/2000) How could I incorporate the voices of the African-American staff without muting the voices of the psychiatric survivors? This work is first and foremost the history of African-American psychiatric survivors. Future works will need to explore the intersections of power, race, class, mental status in the complicated relationships of African-American staff and patients. There is a deep and painful story to tell about the ways that people who wore our face were used as the tools of day-to-day oppression. There are also powerful stories of resistance and healing that came out of the shared experience of racism for survivors and staff.

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I remember a brief conversation with an African-American woman who recently retired from Central State Hospital as she described her horror at lining up female patients for shock treatment and her helplessness over the sterilization of African-American adolescent girls. As she spoke with me, an elderly white man entered the room and she whispered, "That's the shock doctor." I could barely contain my rage at this man and missed a valuable opportunity to get firsthand information regarding the eugenics program at the hospital. At that moment, there was not room for his oppressive power in my history. These are some of the issues that need to be addressed as we embark on a full and honest telling of the psychiatric history of African-Americans.

Oral History Archives

I hope that this monograph will build on the existing oral history projects in New York, Massachusetts and other states. Even if the existing projects are not exclusively devoted to capturing the experiences of African-American people, we need to participate to ensure that our voices are amplified in the re-telling of psychiatric history from a survivor perspective. We have to collaborate with our allies to create archives to preserve and disseminate our stories of survival and recovery. Wherever you are right now, you can build on the process by taping your own story, and creating opportunities to educate other survivors about the critical need to record our history. Start with the elders because we could soon lose their voices, but do not neglect the stories of young survivors who are a crucial thread in the weaving our collective story.

Oral History as Activism

Creating a place to tell our truths is an act of self-love, liberation and reclamation of our full history. As African-American survivors we need to render ourselves visible to the psychiatric community, the historical community, the c/s/x community, the wider African-American community and, most importantly, to ourselves. I first shared my initial work on *In Our Own Voice* at a national c/s/x conference in Nashville, Tennessee, in October 2000. I was moved by the words of an African-American male participant who stated that "This was the first time that I have felt validated at one of these conferences." In that room, a new level of healing and energy emerged as we began to grieve and celebrate our history. The group decided to gather later in that evening to explore the formation of a national African-American survivor organization. The energy and leadership for such an organization existed before we entered the workshop, but the sharing of our history provided a

deeper recognition of where we have been as people and what we need to do to continue the liberation process as African-American psychiatric survivors.

It is important for us to ground our political movements in a firm understanding of history because the forces of oppression that have so effectively silenced and separated us benefit from our ignorance regarding our past abuses and successes. The medicalization of mental illness and confidentiality laws have reduced our experiences with madness (as a mental illness and as an expression of outrage) to an individual illness rather than part of a larger social and political response to oppression and invisibility. It is difficult to listen to the history of African-American survivors without feeling intense rage and profound sadness. We can be torn apart or immobilized by these feelings or we can use them as a force to unite and mobilize us in our search for the truth, a past and present truth of our experiences as African-American psychiatric survivors.

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Chapter IV: In Search of Our History

The exploration of African-American psychiatric history does not necessarily require you to travel. You can find a significant amount of information at your local library and via the Internet. Since most survivors do not have lots of resources, we have to maximize the opportunities to conduct research in our own backyards and to connect with other survivor/historians to build a body of information that accurately represents our experiences in the psychiatric system. I will highlight several local stories that need further exploration:

Malaga Island (Maine)—This was the site of a racially mixed settlement founded in 1794 and destroyed by the state of Maine in 1912 after its residents were declared feeble-minded and relocated to the Maine School for Feeble-minded or other locations. The real motivation for the relocation was racism and land-grab. In a final brutal act to obliterate the history of Malaga Island, the state destroyed all of the structures on the island and exhumed the bones of the dead, placed them in five large caskets and reburied them on the grounds of the state home. (Barry, 1980)

Rusk State Hospital (Texas)—In 1919, this former prison was designated as the state hospital for the "Colored insane." More information is needed about the history of the facility, including survivor perspectives on the 1955 uprising in the maximum security unit led by nineteen-year old Ben Riley. Any detail on Ben Riley's life after the riot would be an important addition to African-American psychiatric history.

Colored Hospitals—We need to identify all freestanding facilities for the "colored insane." When I began this project, I was aware of only two facilities, Eastern Hospital for the Colored Insane in Petersburg, Virginia, and the Asylum for the Colored Insane in Goldsboro, North Carolina. I have since learned of other facilities throughout the county. Check the history of your state to see if there were any segregated facilities. Investigate the experiences of African-Americans in segregated facilities that house African-American and White psychiatric survivors. After reading several reports about Central State Hospital in Georgia's colony farm, I was shocked to find that it was operated exclusively with African-American labor after talking with a staff member who worked at the institution for nearly forty years. The official records failed to note the race of the patients producing all of the food for state hospital complex.

Psychosurgery—There is a need for extensive review of the U.S. government's funding of research into psychosurgery. An Internet article on the brief history of the lobotomy noted that in 1949, staff at Rusk State Hospital in Texas (where Walter Freeman, the leading American proponent of lobotomies, had visited earlier in the year) were planning 450 ice-pick lobotomies before the year was out. (Youngson and Schott 1996)

In the 1960s, J.O. Andy of University of Mississippi at Jackson conducted psychosurgery on African-American children as young as age five who were diagnosed as aggressive and hyperactive. (Breggin on-line reference).

Slave Narratives—A more careful review of existing slave narratives should be conducted to extract information regarding mental illness and the treatment of "insane" slaves. We can also collect information regarding the psychological impact of slavery and strategies used by slaves to deal with emotional distress.

Civil Rights Era—Ola Mae Clemons is not the only civil rights activist to struggle with the emotional trauma of abuse and oppression. We need oral history accounts of the psychological trauma of oppression and resistance, including negative impact of nonviolent responses to oppressive behavior. Dr. Alvin Poussaint noted in an interview with me in October 2000 that civil rights organizers used a variety of strategies, including "soul sessions," debriefing and consciousness-raising discussions, to support civil rights activists. The offcial African-American history is reluctant to embrace the individual emotional casualties of the civil rights struggle. That resistance to inclusion of our "wounded warriors" must be addressed within the African-American community.

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Psychiatric Liberation Movement—African-American survivors have always resisted oppression and we can no longer remain silent regarding the white-washing of the official records of psychiatric liberation movement. We have to remind ourselves, and our white allies in the struggle, of the contributions and resistance of African-Americans and other survivors of color. We have to tell the stories of individual and collective struggles that never made the pages of the local newspaper or *Madness Network News*. African-Americans can use notices in local papers, Internet message boards and flyers at consumer conferences to locate survivors who were engaged in individual and collective resistance in the late sixties and early seventies. Recording the stories of these individuals allows us to "re-member" our history as active participants in the psychiatric liberation movement. As Jill Nelson notes in her collection of essays on Black women, "The truth is, each of us is the leadership, and as much as changes were made by those whom we call heroes, they were made even more by everyday people who lived quiet lives, often as second-class citizens, softly went about their business and, when asked, stood for what was right." (Nelson, 1997 p. 16) We have to reclaim our voice and our experiences, because without them we will continue to live dismembered lives that do not honor our power and our survival skills.

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Getting Started

Internet Sources

The Internet is a crucial tool for conducting historical research. There are thousands of websites that can provide you with surprising information regarding African-Americans, mental illness and resistance. Do not limit yourself to one search engine (e.g., Alta Vista, Yahoo, Ask Jeeves, etc.) since you could miss valuable links to sites that are not included in a particular search engine.

Internet searches are based on key words. I learned the hard way to release my sense of political correctness. After entering variations of "African-Americans," "Black," "Mental Illness," and "Psychiatry" with limited success, I entered "Colored AND Insane AND Asylum" and found several hundred listings. If you are conducting historical research you will have to use the language of that period to pull up the documents. Be sure to save sites under your favorites list so that you can return to them in the future.

I found it less useful to search with the word "Nigger" in the search string. This tends to pull up few legitimate sites but *hundreds* of hate group sites. We have enough to worry about as a people, so avoid those sites if you can.

A few sites of interest were these:

http://cchr.org/racism.pooaa1.htm

A website highlighting the psychiatric oppression of African-Americans, this was created by the Citizens Commission on Human Rights, which is affiliated with the Church of Scientology. This well-documented site offers an overview of the experiences of African-Americans within psychiatric systems.

http://www.springgrove.com/history.html

A very informative website created by the Spring Grove Hospital Center, this covers the history of the Spring Grove Hospital in Maryland. The site includes information regarding the Crownsville Hospital ("colored insane") and the experiences of African-Americans at Spring Grove. The website includes photographs and a photocopy of an intake assessment conducted on an African-American patient.

http://innercity.org.holt.slavechron.html

Giving a fairly detailed overview of slavery in America, this site provides important background information to assist consumers in understanding the social, political and economic context of the period as it applies to psychiatric survivors.

http://cwu.edu/~warren/addenda.html

Although disappointing due to the lack of references to the experiences of African Americans, this site does provide important background information of the evolution of the field of psychology.

http://home.earthlink.net/~openbook/history.mental.therapy.html

This brief history of mental therapy compiled by Robert Meinsma prints out in ninety-two pages. The amazing chronology begins in the 6th Century BC and concludes in 1990. Out of nearly one thousand entries, there are five references to Africans or African Americans. This site is very worthwhile in its overview of the eugenics movement in Nazi Germany (imported from the United States) and psychosurgery in America.

http://breggin.com/racistfedpol.html

This website is operated by the Center for the Study of Psychiatry and Psychology and provides a summary of Dr. Peter Breggin's campaign against the U.S. government's various violence initiatives targeting African-Americans.

http://mindfreedom.org

This website is sponsored by Support Coalition International and keeps up-to-date reports of human-rights violations in psychiatry including the court ordered, forced electroshock of Paul Henri Thomas—an African-American activist at New York's Pilgrim State Hospital.

Books

Nonfiction

Your local public library or African-American research library can be an excellent resource for locating materials. Conduct a literature review to find out what materials are available on-site and what can be borrowed through interlibrary loans. Again, be sure to use a variety of key words, including "Colored" and "Negro," to locate resource material. Amazon.com can be a useful tool for searching for books without any obligation to buy them from the company.

I was surprised at how little information on mental illness was available at the local African-American research library. One of the librarians was very interested in my project and provided me with extraordinary assistance but we still could not find very many books or articles on mental illness. I encourage readers to check out their local African-American museums and research institutions to confirm the representation of African-American psychiatric survivors in our historical archives.

I found the following books extremely helpful in my background research:

Bennett, Jr., Lerone. *Before the Mayflower: A History of Black America*. New York: Penguin Books, 1985. First published in the USA by Johnson Publishing Company, Inc., 1962.

Cranford, M.D., Peter. *But for the Grace of God*. Augusta, GA: Pyramid Press, 1981.

Gamwell, Lynn, and Tomes, Nancy. *Madness in America: Cultural and Medical Perceptions of Mental Illness before 1914*. Ithaca, New York: Cornell University Press, 1995.

McCandless, Peter. *Moonlight, Magnolias and Madness: Insanity in South Carolina from the Colonial Period to the Progressive Era*. Chapel Hill: University of North Carolina Press, 1996.

Poussaint, M.D., Alvin, and Alexander, Amy. *Lay My Burden Down: Unraveling Suicide and the Mental Health Crisis Among African-Americans*. Boston: Beacon Press, 2000.

Teish, Luisah. *Jambalaya: The Natural Woman's Book of Personal Charms and Practical Rituals*. San Francisco: Harper and Row, 1985.

Fiction

Many truths about the African-American experience first appear in fiction works. I am not real clear about this phenomenon but I suspect that it is easier for African-Americans (and others) to see experiences through the softening lens of fiction. It is also amazing that we can be reading about mental illness and psychiatric oppression and totally miss it in the literature. I experienced this myself in reading *Salt Eaters* by Toni Cade Bambara and *Meridian* by Alice Walker.

I struggled through multiple readings of both of these books until I read *Sisters of the Yam: Black Women and Self Recovery* by bell hooks, where she talks about the psychic wounding that occurs in the lives of Black women (hooks, *Sisters of the Yam*). I had to acknowledge that, in my attempts to block out the pain and trauma that these fictional characters experienced, I had rendered the protagonists invisible. I just did not see the mental illness, oppression and trauma. This speaks to a larger psychological strategy of denial to deal with information and events that overwhelm us as a people. The following books are useful resources in exploring who mental illness among African-Americans is addressed in fiction, which is a useful barometer of cultural acknowledgement of an issue.

Bambera, Toni Cade. *Salt Eaters.* New York: Vintage Books, 1980.

Cleage, Pearl. "Bourbon at the Border." *Flying West and Other Plays.* Theatre Group Communications, 1999.

Naylor, Gloria. *Linden Hills.* New York: Penguin Books, 1986.

Perry, Phyllis Alesia. *Stigmata.* New York: Anchor Books, 1998.

Walker, Alice. *Meridian.* New York: Washington Square Press, 1976.

Magazines

It would be useful to conduct a review of African-American magazines to explore how mental illness is addressed within our communities. I noticed an advertisement in an *Ebony* magazine from the early 1970s for Miles, Nervine that "helps calm his jangled nerves." Obviously there was a market for the product within the African-American community for an ad to run in *Ebony* magazine. I had never heard of the medication before but a reference librarian noted that she remembered a family member using the medicine when she was younger. Magazine articles can provide a vital background regarding the context of African-American lives (or at least a segment of the community) during a given period.

I hope that these resource materials provide readers with a useful starting point for your research. There is so much information that we have yet to uncover but the work has begun and is being taken up by more and more survivors every day. We have to ensure that the rich African-American experience in psychiatric oppression and our ability to recover and heal against all odds in recorded for future generations. As I completed this monograph, I had a chance to talk with Pearl Johnson, who shared with me that she had watched the videotape of her interview several times and continues to be moved by what she shared on the tape and what she has remembered since our interview. I am struck by the profound connection that I feel with this gentle warrior and her courage in the face of potentially soul killing trauma and psychiatric victimization. Pearl and I fantasize about a convening a gathering of African-American women psychiatric survivors to share our stories, offer support and celebrate our existence. She reminds me of the critical value of our history as a balm to heal, as a strategy to organize resistance and as a bold liberatory move to render us visible. I offer this monograph as a belated seventy-first birthday present for Pearl in appreciation of the lessons that she shared with me on the art of survival. In the words of Alice Walker, " Rest. In peace in me the meaning of our lives is still unfolding. Rest."

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Critical Sociology

Disabling Incarceration: Connecting Disability to Divergent Confinements in the USA

Liat Ben-Moshe

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What is This?

Disabling Incarceration: Connecting Disability to Divergent Confinements in the USA

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Abstract
This article suggests the merits of conceptualizing incarceration as including institutionalization in a wide variety of enclosed settings, including prisons, jails, institutions for the intellectually disabled, treatment centers, and psychiatric hospitals. Such formulations conceptualize incarceration as a continuum and a multi-faceted phenomenon. This article will highlight the importance of moving beyond analogies between criminalization, institutionalization and psychiatrization to discuss the intersection of these phenomena, by highlighting several social science perspectives that have integrated these spheres already; taking up an analysis of the political economy of incarceration; and re-examining the reality of prisoners with disabilities in the growing prison machine. Lastly, I propose a re-examination of the forces of trans-incarceration, the move from one carceral edifice such as a psychiatric hospital to another such as a jail. I will demonstrate the ways in which engaging in such intersectional analysis changes the lens from which disability and incarceration are conceptualized and analyzed.

Keywords
disability, intersectionality, mental health, political economy, prisons, critical theory

Introduction

There has been much recent interest among social scientists in the issue of 'mass incarceration' (see for instance Garland, 2001; Gilmore, 2006; Gottschalk, 2006; Pager, 2009; Sim, 2009; Wacquant, 2009; Western, 2006). For the most part, this surge in scholarship, analysis and calls for reform does not include analysis of disability and ableism. One area of sociological analysis that seems to encompass incarceration and disability is in accounts that depict imprisonment of those with psychiatric and developmental disabilities as related to a perceived failure of the

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policy of deinstitutionalization (see Crissey and Rosen, 1986; Dear and Wolch, 1987; Isaac and Armat, 1990; Johnson, 1990; Torrey, 1996; Wacquant, 2009), which will be discussed and critiqued later in relation to forces of trans-incarceration. Another exception to this lacuna is the work of Bernard Harcourt (2006, 2011), which connects research on hospitalization in psychiatric hospitals to research on the growth of the prison machine in the USA.

On the other hand, the vast literature in the growing field of disability studies has paid very little attention to the imprisonment of people with disabilities, especially in North America. One notable exception is work on institutionalization and hospitalization of people with a variety of impairments, written from sociological, historical and phenomenological perspectives (for example Ferguson, 1994; Johnson, 1998; Reaume, 2000). However, very little attention has been given to other forms of incarceration in relation to disability – especially to the increased reliance of the state on prisons and jails, and there is a lack of connection between disability studies literature and the various sociological analyses of the prison-industrial complex, mentioned above.

Although disability studies is a diverse and interdisciplinary field, it seems that it often has a sociological orientation interested in the lived experiences of those with disabilities. Yet there is little research about the lived experience of those incarcerated in a variety of settings including prisons and jails, and analysis of the forces of imprisonment from a disability perspective. Sociology, at least in one of its formulations, should be concerned with finding the people where they are located and explaining their circumstances in ways that they might not be able to see from their location, or garnering people's lived knowledge about their location, which may be unfamiliar to outsiders. Both of these interpretations could be connected back to C. Wright Mills's formulation of the sociological imagination as the ability and the desire to connect one's 'personal trouble' to 'public issues' (Mills, 1959). If sociology and disability studies are indeed concerned with both the lived experience of disabled people and the 'matrix of domination' (Collins, 2000) that sustain ableism, then I propose they need to pay attention to processes of incarceration and imprisonment as major 'public issues' taking place within the global North and South (albeit in different ways). I thus call for a tighter connection between the sociology of disability, or the study of the ontology and phenomenological experiences of disabled people and analysis of ableism, and the critical sociological study of incarceration.

This article will offer several connecting points through which disability and incarceration could be studied. The first is a brief overview of several social science perspectives that have integrated these spheres already. The second takes up an analysis of the political economy of incarceration, encompassing prisons and jails but also institutions and nursing homes. The third connecting point lies in the intersection of incarceration and disability – the reality of prisoners with disabilities in the growing prison machine, especially in North America. Lastly, I propose a re-examination of the forces of trans-incarceration, or the move from one carceral edifice such as a psychiatric hospital to another such as a jail. This analysis will pave the way to a broader and deeper understanding of what incarceration entails, in its varied forms. What underpins all these arguments is the idea that incarceration should be perceived as a continuum, ranging from prisons and jails to institutions for the intellectually disabled,[1] and psychiatric hospitals. I therefore advocate an interpretation of incarceration that yields an analysis which is both nuanced and intersectional from its outset.

Broadening the Scope of Incarceration

The need to combine the discussion on current levels of imprisonment with discussion and data about institutionalization, hospitalization and disablement is imperative for practical, empirical

and theoretical reasons. The most pressing is the need to expand on notions of what comes to be classified as 'incarceration'. This article suggests the merits of conceptualizing incarceration as including institutionalization in a wide variety of enclosed settings, including prisons, jails, detention centers, institutions for the intellectually disabled, treatment centers, and psychiatric hospitals. Such formulations conceptualize incarceration as a continuum and a multi-faceted phenomenon. This analysis is especially pressing because of the immense growth of the prison machine in the USA.

For the first time in US history, in 2008, more than one in 100 American adults was behind bars. In 2009 the adult incarcerated population in prisons and jails in the USA had reached 2,284,900 according to the Bureau of Justice Statistics (BJS, 2010). The USA incarcerates a greater share of its population, 737 per 100,000 residents, than any other country on the planet (Pew Center, 2008). Another whopping 5,018,900 people are under 'community corrections,' which include parole and probation (BJS, 2010). Race, gender and disability play a significant role in incarceration rates. In 2006, Caucasians/whites were imprisoned at a rate of 409 per 100,000 residents; Latinos at 1038 per 100,000 and African-Americans at 2468 per 100,000. The rate for women was 134 per 100,000 residents and for men, 1384 per 100,000. In 2005 more than half of all prison and jail inmates were reported as having a mental health problem. Nearly a quarter of both state prisoners and jail inmates who had a mental health problem, compared to a fifth of those without, had served three or more prior incarcerations (Prison Policy Initiative, 2008). The number of carceral edifices in the USA had grown as well. From 2000 to 2005, the number of state and federal correctional facilities increased by 9 percent, from 1668 to 1821 (BJS, 2008).

In contrast to the constant expansion of prisons, deinstitutionalization and institution closure have been a major policy trend in most US states in the past few decades. Deinstitutionalization of people who were labeled as 'mentally ill' began in the 1950s. The deinstitutionalization in the field of 'mental retardation' gained prominence in the 1970s, although this of course varied by state. The population of people with intellectual disabilities living in large public institutions peaked at 194,650 in 1967. By 2004, this number had declined to 41,653 (Prouty et al., 2005). The trend in deinstitutionalization for people with intellectual disabilities was accompanied by institutional closures across most states. By 2009, the District of Columbia, Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia had closed all of their public institutions for people with developmental disabilities (Lakin et al., 2010). In contrast, 13 states have not closed any such public institutions (Braddock, 2002).

An accompanying shift occurred in the field of mental health with the establishment of the community mental health centers in the 1960s and the closure of large state mental hospitals in most major cities. In 1955, the state mental health population was 559,000, nearly as large on a per capita basis as the prison population today. By 2000, it had fallen to below 100,000, a drop of more than 90 percent (Gottschalk, 2010; Harcourt, 2011). Deinstitutionalization in the field of developmental disabilities occurred about 12 years after the deinstitutionalization of public mental hospitals, and the rate of reduction of use of these facilities was also significantly different between the two processes. In the first 10 years of deinstitutionalization for traditional institutions for those labeled as 'mentally retarded', the institutionalized population was reduced by 30 percent and then averaged about 11 percent a year during the 1970s. At its height, between 1955 and 1965, the deinstitutionalization in psychiatric hospitals reduced the populations by 15 percent only (Lerman, 1985).

Over the years, some of the figures given for deinstitutionalization of public institutions have been misleading, as significant proportions of people were transferred to other types of institutions including nursing homes. In 2009, for instance, 12,475 people with developmental disabilities

lived in state operated community residential settings with 15 or fewer residents. In addition, between 1977 and 2009, the total number of residential settings in which people with developmental disabilities received residential services grew from 11,008 to an estimated 173,042, an increase of 1500 percent (Lakin et al., 2010). Because most of these newer settings are much smaller than the massive institutions of previous decades, they are not typically counted as 'institutional' placements, but due to their daily routines and other aspects of life in these settings, many people with disabilities, family members, and advocates consider them to be mini-institutions within the community (Center on Human Policy, 2004).

From this critical intersection, it may not be surprising to also learn that physically, many institutions for those labeled as psychiatrically or developmentally disabled that closed down during the 1980s actually re-opened a few years later as prisons. Alabama turned three-quarters of its closed institutions (which closed in 2003) into correctional facilities (the fourth quarter's use is undetermined). Illinois closed seven institutions, two of which became correctional facilities and a third a women's prison. New York State had the absolute largest number of institutions in the USA, seventeen of which closed between 1970 and 2010. Most of them were left as is, with future usage undetermined, but at least two became correctional facilities (Braddock et al., 2008). These figures, although not comprehensive by any means, serve to highlight the cyclical nature of social control and the persistent nature of incarceration as a strategy to categorize and keep out 'undesirable' populations.

I want to be clear here, that proposing a more thoroughly 'intersectional' history is distinct from proposing that ableism and racism, or asylums and prisons, are the same. It is the similarities and the distinctions that are important to attend to, in terms of rationalizations, in terms of practices associated with them, and also in terms of the effects on the people who are incarcerated in diverse sites of confinement. For example, the criminal justice system seems to offer certain protections to the accused and the prisoner, such as due process during the trial and sentencing procedures, a sentence of a specified duration. However, medical institutions allow the compulsory admittance of patients against their will based only on a medical diagnosis, an indefinite time of commitment, and 'treatments' that are both painful and harmful, such as extended periods of isolation, physical restraints, and electric shock 'therapy'. In addition, the government and the public assume medical 'treatment' is in the best interests of both the patient and society, and great autonomy is given to physicians to determine the best course of treatment (Conrad and Schneider, 1992; Goffman, 1961; Snyder and Mitchell, 2006). Incarceration in prisons, however, seems to be operating more under the discourses of punishment and retribution, rather than rehabilitation. This framework has its own lethal effects on the lives of those incarcerated and formerly incarcerated, but it does not necessarily operate under the same processes as medicalized settings, although both settings have many similarities (Chapman et al., forthcoming).

Connecting Institutionalization and Imprisonment in the Social Sciences

On a theoretical level, the imperative to understand incarceration through both the prism of the prison but also that of the institution, as this article suggests, is crucial to understanding the underlying relations that legitimate confinement in a variety of settings. Such analysis also underscores the relation between penal and medical notions of danger, as they relate to both criminalization and medicalization and labeling. Historically, the connection between imprisonment and definitions of 'abnormality' seems to have arisen out of a new configuration of notions of danger.

From the 19th century the webs of the medical and the judicial start to intertwine with the rise of a hybrid discourse, according to Foucault (2003). Its hybridity lies not just in the sense of amalgamation of several discourses (legal, medical) but also in the creation of a new power/ knowledge structure in which 'doctors laying claim to judicial power and judges laying claim to medical power' (2003: 39) lay down an intertwined system of surveillance, which includes psychiatric progress reports on the incarcerated, examination in court of the accused, and surveillance of 'at risk' groups. According to Foucault (2003), this medico-judicial discourse does not originate from medicine or law or in between, but from another external discourse – that of abnormality. The power of normalization is cloaked by medical notions of illness and legal notions of recidivism. The history of treatment and categorization of those labeled as feeble-minded, and later mentally retarded, is also paved with cobblestones of notions of social danger, as prominent eugenicists tried to 'scientifically' establish that those whom they characterized as feebleminded had a tendency to commit violent crimes. In the late 19th century, as the eugenics movement gained momentum, it was declared that all feebleminded people were potential criminals (Rafter, 1997; Trent, 1995).

Spaces of confinement themselves, such as psychiatric hospitals, poorhouses, prisons and institutions for those labeled as 'mentally retarded', could also be perceived as operating on similar logic, from a variety of perspectives. Foucault analyzes their discursive formations and effects as docile making and producing techniques of governance and social control (1995). The 'remarkable continuity of confinement' (Harcourt, 2006) is also discussed as part of a revisionist social history of places of confinement, offered by Rothman (1971), Grob (1972, 1983), Scull (1979, 1989) and Foucault (1965, 1987, 1995) and amended by feminist historians and criminologists such as Rafter (2004) and Kurshan (1996). The revisionist narrative marked a shift from perspectives that saw asylums and prisons as reforming and benevolent, to more nuanced accounts that critiqued both the consequences and intentions of reform efforts that ended in mass incarceration. Interestingly, this neo-historiography of the institution and prison was written, and battled, by historians and other intellectuals at a time when these institutions started to lose their legitimacy. Most of these accounts were produced in the 1960s and 1970s when larger exposes, lawsuits, novels, movies and ethnographies came out to reveal the decrepit conditions of asylums, hospitals and prisons. These included Erving Goffman's *Asylums* (1961), the novel made into a Hollywood film *One flew Over the Cuckoo's Nest* (Kesey, 1962), Burton Blatt's exposé *Christmas in Purgatory* (Blatt and Kaplan, 1974), the riots in Attica prison, and lawsuits on behalf of prisoners and inmates in state institutions. Therefore, the debates over the reasons and usefulness of asylums in the past should be read as directly tied to debates over decarceration and re-institutionalization at present. The premise that all these writings share is an understanding of incarceration as a continuum and not an isolated phenomenon that can be understood by engaging with only one locale.

Goffman's analysis became a popularized sociological account that analyzed all such edifices as 'total institutions,' in which the incarcerated populations are subjected to stripping of their identities and processes of dehumanization (Goffman, 1961). In addition, the citizenship and personhood of those incarcerated is questioned when living in such institutions. This can be done in the form of taking away or denying voting rights, as is the case for felons and many people with labels of intellectual disabilities, or for women, denying reproductive rights when living in prisons and nursing homes. These populations were also targets of medical experiments in institutions and prisons. Such connections, which stress the similarities of total institutions beg us also to emphasize the importance of moving away from analogies (institutions are like prisons for example) into thinking more intersectionally about their interrelated nature.

Imprisonment in prisons and in institutions are not only related in a theoretical or historical realm. On an empirical level, Harcourt (2006) emphasizes that using an aggregated incarceration rate, which includes data from hospitalization and imprisonment combined, yields very different results and implications for research and policy. Harcourt (2006) laments that none of the above literature, which connected prisons and institutions (for example the work of Foucault and other historians of asylums, the work of Goffman on total institutions, etc), made its way to social scientific research, especially to its empirical/quantitative dimension (with the exception of studies that look into the phenomenon of trans-incarceration, discussed later). In other words, none of the studies that include confinement as an independent variable includes institutionalization in its measure and definition of confinement/incarceration. In social science research, including criminology, the convention is to think of confinement in terms of placement in jails and prisons, therefore reinforcing a skewed interpretation of 'the rise in incarceration' in the USA. Under this interpretation, the first half of the 20th century is conceived as an era of relative stability in terms of incarceration, with an explosion in this area in the 1980s onward, in the form of immense growth in the capacity of prisons and jails. However, as Harcourt (2006) suggests, if the data on mental hospitalization and institutionalization were also covered in such studies under the prism of incarceration, then the 'rise in incarceration' would have reached its peak in 1955, when mental hospitals reached their highest capacity. Put differently, the incarceration rates in prisons and jails today (although appallingly high by any standards) barely scrape the levels of incarceration during the early part of the 20th century because of the then massive confinement in hospitals.

Therefore, Harcourt (2006) argues for the use of aggregated incarceration rates, by using figures for imprisonment and institutionalization combined, for all future research that examines the relation of confinement to other factors such as homicide, employment, education, crime, etc. Not to do so is to look at only a partial picture of both confinement and incapacitation and also not to take seriously the theoretical and historical perspectives that conceptualize incarceration more expansively. What needs to be empirically assessed, then, is not 'the rise in incarceration' but the systemic and lingering effects of the continuity of confinement in modern times. What such arguments highlight is the need to reconceptualize institutionalization and imprisonment as not merely analogues but as in fact interconnected, in their logic, historical enactment and social effects. The theoretical and policy implications of such interconnectedness will also necessitate bringing in disability (psychiatric, developmental, physical, etc.) as a focus in studies on incarceration, as well as working out questions of criminality and danger in studies of institutionalization and disablement.

Political Economy and the Institution-Prison-Industrial Complex

Political economy could be applied as a useful framework from which to uncover the connections between the construction of disability and criminality, as another explanatory scheme for the growing usage of confinement in capitalist societies. Class based analysis of disability urges us to shift our understanding of disability oppression from discussions of stigma and deviance to that of systematic economic exclusion of people with disabilities. In such Marxist inspired accounts, the conditions of being (socio-economic location) are seen as core producers of particular ableist attitudes and ideologies, and not the other way around. Thus, several disability studies scholars point to the need to move beyond models of disability rights to revealing the systematic exclusion of people with disabilities from sites of production, exchange and, to a lesser extent, consumption (Ben-Moshe et al., 2009; McRuer, 2006; Oliver, 1990; Russell, 1998, 2001). Charlton (1998) sees disabled people as surplus population, those who do not even serve as part of what Marx termed

the 'reserve army of labor', a resource tapped into during economic expansion or crisis. They are essentially the underclass. In fact, the definition of unemployment itself historically excludes disabled people, illegal immigrants, retired people (who often wish to work), and women (who do unpaid labor).

Under a neo-Marxist analysis, disability is an ideology upon which the capitalist system rests, because it can regulate and control the unequal distribution of surplus by invoking biological difference as the 'natural' cause of inequality (Erevelles, 1996; Stone, 1994). Work is central to industrial societies, not only as means to get life's necessities but also to establish certain kinds of relations with others, which are valued within these societies (Oliver, 1990). Industrialization and the advent of capitalism not only posed a problem for disabled people's participation in the work force (which now required greater speed, stamina and rigid production norms), but also excluded disability as part of mainstream society. In addition, disabled people were often blamed for the changed mode of production (Nibert, 1995). Hierarchical relations that were once a divine right became an economic rule that need to be justified by such ideologies as eugenics, meritocracy and the increasing need for 'skilled and educated' labor, which exclude those who are labeled as uneducable because of disability and other factors (Nibert, 1995). Thus, disabled people have increasingly found themselves marginalized within segregated settings such as institutions and 'special' education (Oliver, 1990). Under this formulation, disabled people mark, with their different bodies and minds, the boundaries of normalcy. They serve as an ideological reminder of the fate of those who do not participate in capitalist production. The notion of disability is so intertwined with perceived inability to work that if a person is able to work, they cannot be regarded as disabled, according to social security administration in the USA, for instance.

All societies function through principles that distribute goods and services among the entire population. Stone (1994) argues that in capitalist societies the major distributive mechanism is work – but not all are willing or able to work. Therefore a second distributive mechanism is established, which is based on need. With the rise of capitalism, disability became the category through which people are measured as need based or work based. Such interpretations dispel the common belief that people with disabilities are not productive under the capitalist system, since they do not hold jobs. In fact, many (including policy makers) believe that disabled people are a strain on the economy, especially under neoliberal ideology. But political economists argue that disability supports a whole industry of professionals that keeps the economy afloat, such as service providers, case managers, medical professionals, health care specialists, etc. (Charlton, 1998; Oliver, 1990).

Human services have traditionally been regarded as moral enterprises that service and assist people in need. However, according to Wolfensberger (1989), the latent function of this industry is self preservation and expansion – often at the expense of the users of these services. As Oliver explains so eloquently:

> [under capitalism] the production of the category of disability is no different from the production of motor cars or hamburgers. Each has an industry, whether it be the car, fast food, or human service industry. Each industry has a workforce which has a vested interest in producing their product in particular ways and in exerting as much control over the process of production as possible. (Oliver, 1990: 126)

Human services are a major component of contemporary western economy, especially with the decline in agriculture and manufacturing jobs and must remain significant in order to perpetuate the structure of modern post-industrial societies (Wolfensberger, 1989). Unemployment and low incomes are then maintained by a class whose employment is derived from these deprived populations, such as case manager, social workers, probation officers, and health care/mental health administrators.

The advent of neoliberalism and workfare programs shifted the discourse around 'deserving and undeserving' populations so that today in many 'industrialized' OECD countries even those perceived as deserving of public assistance, such as those who are deemed disabled, are being pushed into the labor market through workfare programs, despite the lack of jobs, and the inaccessibility of the capitalist enterprise as a whole. This discourse shifts the understanding of disability as a category under 'the reserve army of labor' to a population being surveilled for political-economic reasons. The increased surveillance of welfare recipients (see Wacquant, 2009) can also be observed today as used on disability benefits recipients especially by agencies granting the services with the use of home visits, complicated verification systems and even the hiring of investigators to follow specific recipients to ensure the authenticity of their disability. Loic Wacquant (2009) further discusses the ways in which workfare and prisonfare (increased criminalization and incarceration of unwanted populations mostly based on race and class) operate as the left and right arm of the state, and cannot be separated. He asserts that the failure of welfare and workfare to alleviate poverty implies that the main aim of such policies is not to decrease poverty levels but to survey and surveille the poor and keep them as invisible as possible from the social and cultural landscape (Wacquant, 2009). The second mechanism used to criminalize the poor is the increased use of incarceration. This tactic makes the underemployed, including those who are disabled, disappear from the public scene, both literally (as they are warehoused in a variety of internments) and figuratively in statistics and policy analysis of unemployment, which do not count prisoners and institutionalized members.

I suggest that the forces of incarceration of disabled people should be understood under the growth of both the prison industry and the institution-industrial complex, in the form of a growing private industry of nursing homes, boarding homes, for-profit psychiatric hospitals and group homes. Some of the major corporations in the institution/hospital industry in North America are Res-Care; Beverly Enterprises of Fort Smith, which employs more people than the entire automobile industry; Healthsouth rehabilitation corporation; Columbia/HCA hospital chain; Humana, and Summit Health. Disability and deinstitutionalization advocates claim that although costs vary by state and place of confinement (state funded, private, or veteran run), it is cheaper to financially sustain a disabled person, with supports, in the community than it is to institutionalize them (Russell, 1998). These cost estimates raise an ongoing debate – as it is hard to compare community placement, with minimal supports as it is now, to institutions that have an array of services embedded within their costs. What is clear though, from looking at governmental policies, is that the institutional bias (i.e. the impetus to institutionalize people with disabilities instead of providing them with supports to live in the community with the same funds) is embedded in Medicaid policies in the USA, for example, and also represented in current legislation and lobbying efforts (Lerman, 1985). The American Health Care Association, for instance, which represents for-profit nursing homes and care facilities, is one of the biggest financial contributors to the campaigns of federal candidates (Russell, 1998).

This bias means that public funds (in the form of benefits or waivers) goes towards institutions, nursing homes or group homes but not to the person who benefits from these services directly. In the USA, the introduction of Medicaid waivers mostly applies to alternative institutions (nursing homes, hostels) and not alternative care. There is a lack of reimbursements that could cover services such as non-hospitalization long term treatment, day and vocational habilitation, advocacy and support for living in the community. The consequence is that most people with disabilities do not have real choices in terms of whether and with whom they would like to live, if their main source of funding is federal benefits. Many disability advocacy organizations in the USA, most prominently ADAPT, therefore support any initiatives, such as Money Follows the Person,

Medicaid Community Attendant Services Act (MiCasa) and the Community Choice Act, that enable people to utilize their benefits and waivers as they see fit, to hire their own aids and to enable them to live an integrated life in community settings of their own choosing.

In short, in post-industrial times, disablement has become big business. A single impaired body generates tens of thousands of dollars in annual revenues in an institution. From the point of view of the institution-industrial complex, disabled people are worth more to the gross domestic product when occupying institutional 'beds' than they are in their own homes (Russell and Stewart, 2001). Capitalism has found a solution to the 'problem' of unproductiveness, for those who are not perceived as laborers. Their bodies generate revenues when placed in institutional beds, such as large institutions, nursing homes, prisons and (some) group homes. This is the logic of handicapitalism, as Russell (1998) refers to it. This political-economic analysis of institutionalization should be further investigated by scholars who are interested in understanding the phenomenon of mass incarceration through an intersectional lens.

Disability Studies, Sociology and Psychiatric and Developmental Disabilities

The field of disability studies can be credited for 'shifting the margin to the center' (hooks, 2000) in relation to the critical study of the construction of normalcy and lived reality of disability. Feminists and critical analysis of disability brought to the forefront a new conceptualization of disability, not just as a socially excluded category, but as an embodied identity (Thomson, 1997; Wendell, 1996). This focus on embodiment challenges the medical model of disability, which conceives of disability as a lack and deficiency inherent in non-normative bodies. It also challenges the social model of disability, which encourages us to focus solely on processes of disablement as a critical framework that will end the oppression of people with disabilities (Morris, 2001; Tremain, 2002).

However, one major critique of such an enterprise is the concern of overrepresentation of the body and visible disabilities in the field of disability studies. Such focus obscures the myriad disabilities and impairments that could and should be analyzed under the purview of disability studies. For instance, Rosemarie Garland Thomson's work, which has been central to the field of disability studies, focuses on freak enactments, visible anomalies, ethics of staring, and disability as a visual modality (1997, 2000, 2002, 2009). However, there is very little focus in this formulation of disability studies on cognitive/intellectual, developmental, learning and even psychiatric disabilities. Another noted example could be found in the seminal book *Cultural Locations of Disability* (2006), in which disability studies theorists David Mitchell and Sharon Snyder contend that until the publication of *Abnormal* (2003), Michel Foucault did not explicitly engage with disabled bodies. But what about insane bodies, which are the focus of much of Foucault's work (1965, 1987)? Are they not considered disabled, and if so, why not? Is the purview of disability studies so bound up by the experience of physical impairments that other disabling embodiments become the exception to the rule?

I want to be clear that I am not trying to suggest that the experiences and analysis of various impairments and forms of oppression should be conflated into one meta-field, called disability studies. And I am not suggesting that being psychiatrized or being labeled intellectually disabled or having a physical or sensory disability are all the same. What I am trying to push for is the understanding that the logic of normalcy (Davis, 1995) and compulsory ablebodiedness (McRuer, 2002) operates on all these fronts and needs to be analyzed in concordance with all of these different embodiments and discourses. I suggest that the emergent difference between these

experiences, and now scholarly fields, needs to be studied and understood as a contingency, not taken as an axiom.

There are many commonalities that could be traced between the discourses of disability studies, critical study of developmental disabilities and mad studies. Firstly, of course, one needs to acknowledge the intersectional nature of oppressions, impairments and ways of being in the world. Therefore, many people with sensory or developmental disabilities, for example, feel the stress of living in an ableist and inaccessible world and thus may share experiences with those who are psychiatrized or become psychiatrized themselves. In addition, many people who have been psychiatrized or institutionalized may have physical or sensory impairments due to the effects of medications and the nature of being incarcerated in hospitals (Beresford, 2000).

Most notably, many in these movements share goals of fighting for 're-symbolization' and meaning (Thomson, 2002). For instance, these fields share a process by which terminology such as 'crip' and 'mad' have been reclaimed and reaffirmed as legitimate, not to mention chic, identity formations as opposed to diagnostic labels that signal lack and pathology (Lewis, 2006). The disabled/psychiatrized identity is thus seen either in a matter of fact way or as a valued identity one possesses, in a similar vein to queer identities or the new concept of 'deaf gain' as opposed to 'hearing loss' within deaf culture (Bauman and Murray, 2009). These processes can also be observed, albeit in different ways, in recent campaigns in the USA to end the use of the 'R word'[2] as it is seen by self-advocates[3] as oppressive and antiquated. Moreover, such frameworks emphasize systemic ways of oppression based on perceived difference, as oppose to other frameworks that put the source of blame and stress on the person and not on social structures. In disability studies, such systems of oppression have been termed forms of handicapism (Bogdan and Biklen, 1977), ableism, normalcy (Davis, 1995) and disablement (Oliver, 1990), and in mad studies the emphasis is on sanism or mentalism (Chamberlin, 1978; Perlin, 2000).

Another connecting point between these various scholarly discourses is that in the public's eye, and often in public policy, people who are psychiatrized and those who are labeled as intellectually or physically disabled all share a common label in administrative categorization, the gathering of statistics and bureaucratic definitions – the label of 'disability' (Beresford, 2000). This is done despite the resistance of some of these groups seeking to escape from the label of disability, as an administrative label or self-definition. For instance, many with psychiatric labels do not identify as disabled and see their life circumstances as significantly different from those of people with disabilities (Lewis, 2006). But even if certain groups or individuals resist the impetus to collide all these categories, often in social policy, legislation and service provision they are lumped together nonetheless. This collision of many subject formations into one administrative category can be seen as a bio-political tool of population control and management, and therefore as a form of governmentality (Foucault, 2010).[4]

However, this process also allows for the creation of powerful new coalitions that have the potential to implode or resist these categorizations from within. All these counter-hegemonic discourses resist the impetus of normalization (Davis, 2002), medicalization and the authority of medical 'experts' (Foucault, 1965; Zola, 1991) and especially labeling for diagnostic and prescriptive use on the bodies and minds of disabled people. They resist the trumping of narratives of cure, and insist on access, social justice and rights instead (or in some formulations- in addition). Most importantly, these discourses and scholarly fields break the dichotomy between 'normal' and 'pathological' and leave bio-diversity as a continuum of ways of living in the world, and not a binary with hierarchies attached.

I thus argue that disability studies could benefit immensely by actively taking up the theorizations and lived experiences in the field of developmental disability and mad studies. In relation

to the sociological study of incarceration, what such expansive formulations achieve is an understanding of incarceration in its broadest sense in relation to hospitalization, institutionalization and imprisonment and a fuller understanding of the forces that construct medicalization and criminalization.

Trans-incarceration: From Balloon Theory to Reconceptualizing Incarceration

Another area of research at the intersection of institutionalization and incarceration arises from the idea that after deinstitutionalization many of those deinstitutionalized ended up in prisons and jails. This move from one carceral space to another has been termed trans-incarceration and is much debated in the sociological literature. When looking at general trends, it is easy to interpret the data as a hypothesis of medicalization giving way to criminalization over time. When examining incarceration rates, one can stipulate that psychiatry had the strongest hold on taking charge of social problems in the first half of the 20th century, culminating in over a quarter of a million people in mental hospitals in 1955. From the 1960s the mental inmates' population decreased but the prison population increased (Liska et al., 1999). The shrinkage of the safety net from the Reagan era to the 1990s, coupled with increased federal expansion of the corrections operation created in essence a tradeoff between social services and incarceration. Wacquant (2009) and others (see Dear and Wolch, 1987; Isaac and Armat, 1990; Torrey, 1996) thus argue that the shift from medical and social services to penal and surveillance measures can be seen in the treatment of people with psychiatric disabilities, which reiterates the claims that deinstitutionalization resulted in re-incarceration of mentally ill people in jails.

This relationship, of reversal of the trends between the mental health and the criminal systems, is hardly new, however, and has been studied over the years by many social scientists who have nicknamed this phenomenon 'the balloon theory'. As early as 1939, Penrose suggested that social control evolves from incarcerating people to treating people, therefore suggesting an inverse relationship between the mental health and prison systems. Since then, this hypothesis has been tested numerous times with inconsistent results. Trans-institutionalization of juvenile offenders happened repeatedly in the 1970s, when reform schools depopulated while numbers in psychiatric or child welfare institutions increased. Jerry Miller, who was the commissioner who decided on decarceration of all juvenile facilities in the state of Massachusetts in the 1970s, comments that this was not the same kids simply being moved from one institution to another, but instead represents a system change that is a core component of the institutional system (Miller, 1991). Institutions tend to reproduce themselves, only the populations change in the meantime.

The major hypothesis of such claims is that the mental health system reroutes individuals into the criminal justice system, via arrests and placement in jails and prisons. Overall, studies suggest that in relation to arrests, this hypothesis may be corroborated, as the percentage of mental patients with prior arrests had increased from the 1940s to the 1970s. But studies of imprisonment seem less conclusive, suggesting that some inmates end up in jails after being arrested, but not so much in prisons (Liska et al., 1999). The research conducted by Liska et al. (1999) finds no support for the hypothesis that a decrease in hospital capacity would lead to an increase in the capacity of jails and prisons, which they term the 'functional-alternative' thesis. They did find, however, some support for the conduit thesis, which means that the criminal justice system operates as a conduit to the mental health system, but not vice versa. The movement of some people from jails and prisons and into hospitals could be done by official transfers decided upon by a judge and based on a

psychiatric evaluation, or it could be based on less official means such as plea bargains for reduced time or an individual decision that hospital time is better than time in prison.

Steadman et al. (1984) researched the relationship between the mental health and prison systems in the aftermath of deinstitutionalization of psychiatric hospitals. They used both a comparative and a longitudinal approach. Their study randomly selected a total of 3897 male prisoners and 2376 adult male admittees to state mental hospitals from six different states, half from 1968 and the other half from 1978. They gathered full institutional histories for arrests, imprisonment, and state mental hospitalization for each inmate and then compared the system overlap between 1968 and 1978, thus enabling them to measure the extent of trans-institutionalization. Their results indicated that Texas experienced a huge increase, California and Iowa had increases as well, but New York, Arizona, and Massachusetts experienced proportional declines. Steadman et al. (1984) concluded from these data that there was little evidence of massive transfer from mental hospitals to prisons. But they did find evidence to suggest that mental hospitals were becoming more 'criminal', in that the number of mental hospital admittees with one or more prior arrests increased by an average of 40 percent.

Taking incarceration in its broadest terms, (in relation to both prisons and institutions), would entail deconstructing the categories that are used by criminologists, psychiatrists and social scientists. The point will not be to try and find the most accurate way of measuring 'the mentally ill' in prisons and jails, but to ask questions which take into account the blurry line between criminality and medicalization. For instance, instead of discussing 'the rise in incarceration' as a single-faceted phenomenon, examining it in conjunction with previous rates of institutionalization would enable one to see if the criminal justice system widened its net to include those who were previously incarcerated in institutions and asylums (Harcourt, 2006). However, the assumption that these are the same people (i.e. that people were deinstitutionalized and ended up in prison), should also be deconstructed as the demographics of each of these populations as a whole are quite distinct. Over the years, the gender distribution of inmates in mental hospitals tended to be either equal or tended towards overrepresentation of women. However, in terms of imprisonment, the majority of those imprisoned are male. There are differences in terms of age and race/ethnicity as well. Although there is some evidence to suggest that during deinstitutionalization the proportion of people of color had increased for those admitted to mental hospitals, the proportion still stood at about a third at its highest point (Steadman et al., 1984). As should now be clear to anyone familiar with the prison system in the USA, people of color are highly overrepresented, reaching over 50 percent in the early 1990s. Put differently, generally speaking, the inmate population in mental hospitals tended to be white, older and more equally distributed by gender then those incarcerated in prisons (Harcourt, 2006). Therefore, we are not speaking about the same population, but of ways in which the social control function of incarceration retained its importance, but for differing populations.

A critique of Harcourt's pioneering work is that even he, in his call for inclusion and broadening the scope of current research, neglects to take into account the rates of institutionalization in a variety of confinement spaces. The rates of incarceration that he describes are made up of rates of hospitalization in psychiatric hospitals and those of incarceration in prisons. Another huge body of literature and data that is omitted from the analysis is that of incarceration in institutions specifically created for those labeled as 'mentally retarded'.[5] It would be interesting to extend that analysis in terms of aggregated data sets in a similar vein to Harcourt's transfiguration but also to include other institutions such as those for people with developmental disabilities, and nursing homes. Such an analysis would truly broaden the scope of incarceration and take into account the lived experiences of those who are housed in such settings as carceral spaces.

Prisoners with Disabilities at the Intersection

Another set of studies that examine the connection between medicalization, criminalization and imprisonment is the gathering of statistics around the prevalence of disability, especially labels of mental illness and mental retardation, among the imprisoned population. Statistics on 'criminally mentally ill' or people with mental illness diagnoses in jails and prisons are generally hard to come by, especially historically. This is one of the reasons why claims of increasing rates of mental illness in prisons post-deinstitutionalization is hard to support, as there is no comparative data pre-deinstitutionalization that can be used as a baseline for such comparisons. Although several attempts have been made to estimate the number of prisoners who have a psychiatric diagnosis, it is impossible to quantify their number with any degree of precision, even if taking the label of 'mental illness' as a viable construct. The American Psychiatric Association reports in 2000 that 'up to 5% [of prisoners] are actively psychotic' and that as many as one in five prisoners were seriously mentally ill (APA, 2000: xix).

Other attempts to estimate their prevalence appear to have used a substantially more expansive definition of mental illness. The Bureau of Justice Statistics (1999) reports that 16 percent of state prison inmates either identified as having 'a mental condition' or having stayed overnight in a mental hospital. The statistics for women prisoners are particularly stark. The same study by the Bureau of Justice Statistics based on a survey of prisoners, found that '29 percent of white females, 20 percent of black females and 22 percent of Hispanic females in State prison were identified as mentally ill. Nearly four in ten white female inmates aged twenty-four or younger were mentally ill' (BJS, 1999).

Even when taking the construct of 'mental retardation' as a pure label, which is dependent on socio-historical power/knowledge paradigms, there is no precise measurement for the number of prisoners who are labeled as mentally retarded. A policy brief states that while those with intellectual disabilities comprise 2 to 3 percent of the general population, they represent 4 to 10 percent of the prison population, with an even greater number of those in juvenile facilities and in jails (Petersilia, 2000). One study that looked at the number of people with disabilities in state and federal prisons found that less than 1 percent of inmates had physical disabilities while 4.2 percent had 'mental retardation' (Veneziano and Veneziano, 1996). It is also important to note that the construct of 'mental retardation' cannot be entirely separated from that of 'mental illness', as there are many, especially those who end up in prisons and jails, that are labeled as both, and the types of discrimination they are facing is compounded by unfounded beliefs and lack of services in relation to both disabilities.

Analyzing imprisonment from a disability studies lens will necessitate a closer look at the social and economic conditions of disablement and incarceration rather than looking at disability as a cause for criminal acts. Prisoners are not randomly selected and do not represent all statuses of society. The majority of prisoners are poor, and are people of color. Poverty is known to cause a variety of impairments and disabling conditions. In addition it is crucial to emphasize that the prison environment itself is disabling – from hard labor in toxic conditions and materials to closed wards with poor air quality, circulation of drugs and unsanitary needles, and lack of medical equipment and medication (Russell and Stewart, 2001). It is also crucial to take an expansive view of what constitutes 'disability' in such environments. For instance, the high prevalence of HIV/AIDS among prisoners and the various impairments that come with aging in a disabling environment such as a prison, as a result of prolonged sentencing policies, should be analyzed critically by sociologists and disability studies scholars. Disability in this framework is not a natural biological entity, but related to economic and social conditions that lead to an increased chance of both disablement and imprisonment.

Regardless of the percentages, it has become clear that while in prisons or jails, those with disability or psychiatric diagnoses are often discriminated against. Far too frequently, when there is no serious effort to provide mental health treatment, the only semblance of treatment offered is psychotropic medication, and often in such circumstances it is ill prescribed and controlled (see American Association on Mental Retardation, 2005). Because of lack of access, prisoners with physical disabilities cannot leave their cells, including going to the bathroom or showering. The lack of basic human needs in the penal system is brought to full light in the heart wrenching stories of prisoners with disabilities. Like in the case of Newman v. Alabama, finding systemic constitutional violations of prisoners' rights in the Alabama prison system, including the death of a quadriplegic inmate, who spent many months in the hospital confined to a bed, leading to bedsores, which developed maggots from lack of care 'until the stench pervaded the entire ward' (see ADAPT, 2005). What such horrific stories show is not the uniqueness of the disability experience behind bars, but both systemic disablement within society at large and the inherent cruelty and inhumanity of the penal system as a whole.

Similarly, conditions of confinement may cause further mental deterioration in prisoners entering the system with diagnoses of 'mental illness' or intellectual disabilities. Most court cases show that the right to (re)habilitation is often not fulfilled in jails, prisons and institutions, and that this further distresses those incarcerated and worsens their mental and physical health overall. Those incarcerated (in institutions or prisons) with labels of intellectual disabilities may in fact lose crucial life skills that they had before they were imprisoned such as 'loss of the ability to communicate, perform daily self-care, remain physically safe, and to maintain even rudimentary emotional stability' (American Association on Mental Retardation, 2005). Prisoners who are identified as mentally ill or exhibit 'disruptive behaviors' are often sanctioned to 'administrative segregation' in separate units, which are often isolation units. These segregated forms of incarceration, such as supermax or SHU (security housing units), are likely to cause or exacerbate mental and physical ill-health of those incarcerated. Haney (2003) lists 'rage, loss of control, paranoia, hallucinations, and self-mutilations' as some of the adverse effects prisoners secluded in supermax and solitary confinement had experienced.

The reason why these figures are so crucial is because there is much at stake in counting the percentage of disabled prisoners, in terms of research, policy and activism. In terms of policy and legislation, it is clear that if one can prove sufficiently that there is a large percentage of prisoners with a specific disability, then it would require a specific solution such as requesting more hospital units to be built in specific prisons or prescribing more medications on a particular unit. For activists, using statistics that demonstrate the high prevalence of disabled prisoners could lead in several directions. If one is an activist in NAMI (National Alliance of Mental Illness), for instance, then these statistics are used to show that deinstitutionalization failed and that prisons and jails had become a dumping ground for those labeled as mentally ill with the lack of other alternatives. Such campaigns, which have been ongoing since the early 1990s, call in essence for the (re)hospitalization of those with psychiatric diagnosis (see Torrey, 1996 for example). However, if one is an activist in broader or more radical social justice initiatives, they might use these statistics to showcase the cruelty of the criminal 'justice' system and call for the just treatment of all prisoners (such as abolishing the use of isolation units or forced medication overall). The downturn of such arguments, much like those in the calls to abolish the death penalty for those who are labeled as intellectually disabled, is that they can turn into arguments that reproduce ableist rhetoric and may seem to call for the release of some prisoners (i.e. those most disabled) but not others.

Conclusion: The Incarceration Matrix and the Sociological Imagination

This article was intended as a beginning to an overdue conversation between the growing scholarship on incarceration and research in the critical field of disability studies, by conceptualizing disability and incarceration very broadly. Incorporating a variety of forms of disablement within disability studies (in relation to psychiatrization, labeling of those with intellectual disabilities and institutionalization) will hopefully generate more nuanced accounts of what gets codified as disability as well as what gets to be labeled, and researched, as incarceration. Broadening the scope of research on incarceration to include a variety of confinements (such as psychiatric hospitals, nursing homes, institutions for those labeled as intellectually and developmentally disabled) will take into account the work of scholars who have already theorized the carceral along these lines (such as Foucault, Goffman, Scull and others) and can also generate new work in this vein. It will also account for the lived reality of prisoners with disabilities who are caught in the webs of the institution- and prison-industrial complexes. Under this formulation, incarceration is understood as a continuum of carceral edifices, or as an institutional matrix in which disability is a core component, not simply an added category of analysis.

This call for connecting analysis of incarceration with disability is also a call to pay attention to the lives of mostly poor people of color who are still incarcerated worldwide in nursing homes, institutions for those with labels of mental illness and/or intellectual disability and prisons, and bring their perspective to bear on what Chris Bell characterized as 'White disability studies' (2006). My main argument here is that the history of disability is the history of incarceration. Following this argument will lead us back to the original premise of the sociological imagination. As Mills explains, 'The sociological imagination enables us to grasp history and biography and the relations between the two within society. That is its task and its promise' (1959: 6). Therefore, sociologists who study incarceration and those who are interested in the lived experience of people with a variety of disability labels would fare well with a more expansive view of both disability and incarceration.

Acknowledgments

Notes

1 Throughout the article I refer to people with intellectual and developmental disabilities and people with labels of mental illness. For the purposes of this article, these refer to the same two populations but using different terminology derived either from the people first movement (i.e. people with developmental disabilities) or more historically accurate terminology derived from the way people were referred to in public policy up until a few years ago (i.e. the category of mental retardation). Most of the time I choose to use the terms derived from disability studies and labeling theory, which view these categories of 'disability' as socially constructed. I therefore mostly refer to people as 'people labeled as mentally ill' to indicate that I perceive these categorizations as situational and varied over time, culture and power dynamics as to who gets to define and who gets to be defined under these categories.

2 'R word' refers to the use of the category of mental retardation, which is rejected by self-advocates who are labeled by this category and view it as offensive. They push for the abolition of the term and replacing it with terms such as developmental disabilities for administrative use, or others push for no labels as can be seen in the re-emergence of the slogan 'label jars not people' by the People First movement in the USA. See http://www.r-word.org/ for more details.

3   Self advocates are people with labels of intellectual/cognitive disabilities who are involved in disability advocacy and activism.
4   Recent work by Jasbir Puar (2009) further challenges identity politics in disability studies and activism and demonstrates the porous boundaries between capacity endowed and debility laden bodies, by using the categories of risk, statistical probability, and prognosis, which if taken seriously transform our understanding of ability and identity from being an essence into being codifications of risks and their management by subjects and the state.
5   The scope of the larger project, out of which this article is derived, takes seriously Harcourt's suggestion in terms of theoretical and conceptual underpinning that what is considered incarceration includes those incarcerated in prisons, asylums, training schools, institutions for those labeled as intellectually disabled and psychiatric hospitals. It primarily connects the activism of prison abolition and deinstitutionalization as movements that aim to close down 'total institutions' in the USA (see Ben-Moshe, 2011).

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COLORLINES
NEWS FOR ACTION

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Infographic: From Disability to Criminality

Infographic: Erin Zipper

by Erin Zipper, Julianne Hing

Tuesday, May 13 2014, 7:00 AM EST

Editor's note: Our series "Life Cycles of Inequity [http://colorlines.com/life-cycles-of-inequity/] " explores the ways in which inequity impacts the lives of black men. Each month, we focus on a life stage or event in which that impact has been shown to be particularly profound.

This infographic is part of a package focused on implicit bias in schools. Read Julianne Hing's profile of a novel program in Oakland [http://colorlines.com /archives/2014/05/race_disability_and_the_school_to_prison_pipeline.html] that seeks to disentagle the threads of race, disability and discipline. And watch our series' introductory video [http://colorlines.com/archives/2014/05 /life_cycles_of_inequity_a_colorlines_series_on_black_men.html%20] , in which eight young black men describe their own experiences with implicit bias in the classroom.

CRIMINALITY

Select schools nurture an environment that funnels students toward the criminal justice system. Students labeled with a disability and students of color are particularly likely to enter the school-to-prison pipeline.

WHO IS THE MOST VULNERABLE?

Black Students

Students Labeled with Disability

Most at Risk
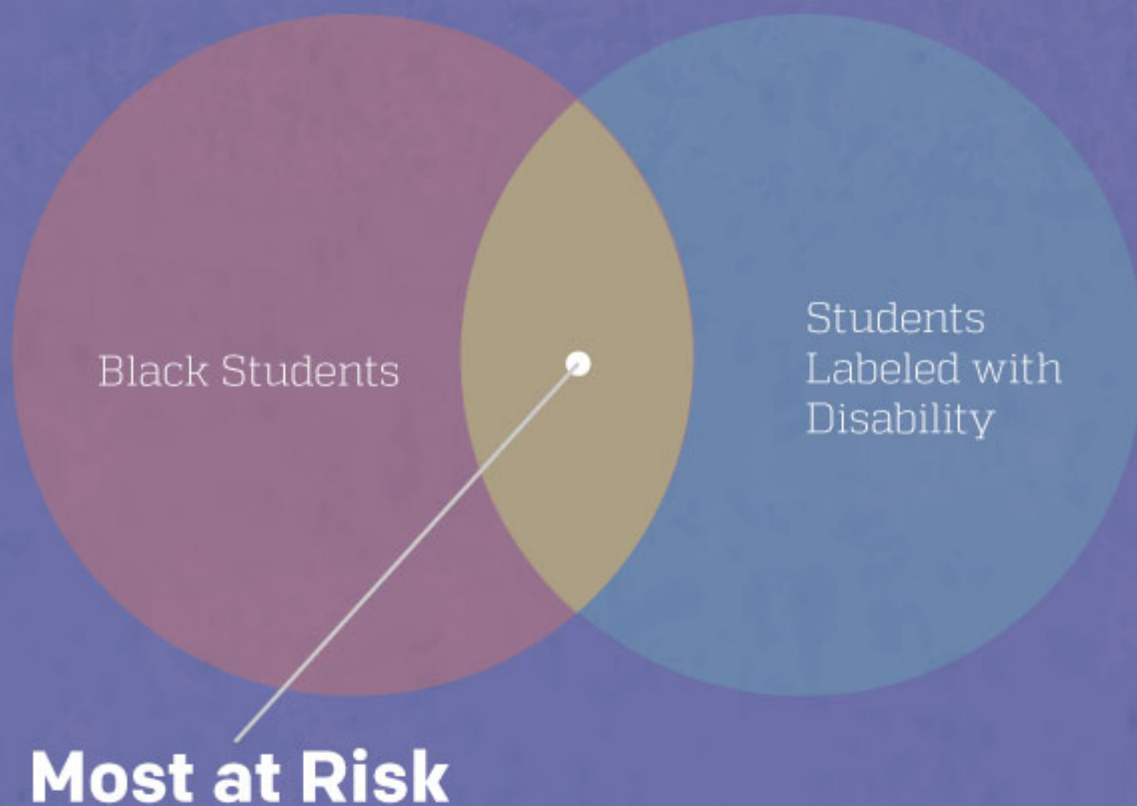
HOW ARE STUDENTS SHUFFLED TOWARDS PRISON?

Cutbacks on Social Workers and Mental Health Resources
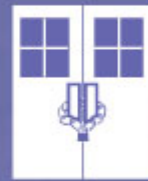
In School Arrests

Police Dogs

Implicit & Explicit Bias

Disengagement Through High Stakes Testing

School Closures

Suspensions

Expulsions

Zero Tolerance Policies

WHAT IS A DISABILITY?

There are over a dozen different ways to be classified as a special education student. Some categories of disibility are diagnosed with much more subjective judgment than others.

EXAMPLES OF SUBJECTIVELY DIAG- NOSED DISABILITIES:

- Emotionally Disturbed

- Learning Disability

- Intellectual Disability

EMOTIONAL DISTURBANCE IS DEFINED AS:

an inability to learn that cannot be explained by intellectual, sensory or health factors.

SYMPTOMS INCLUDE:

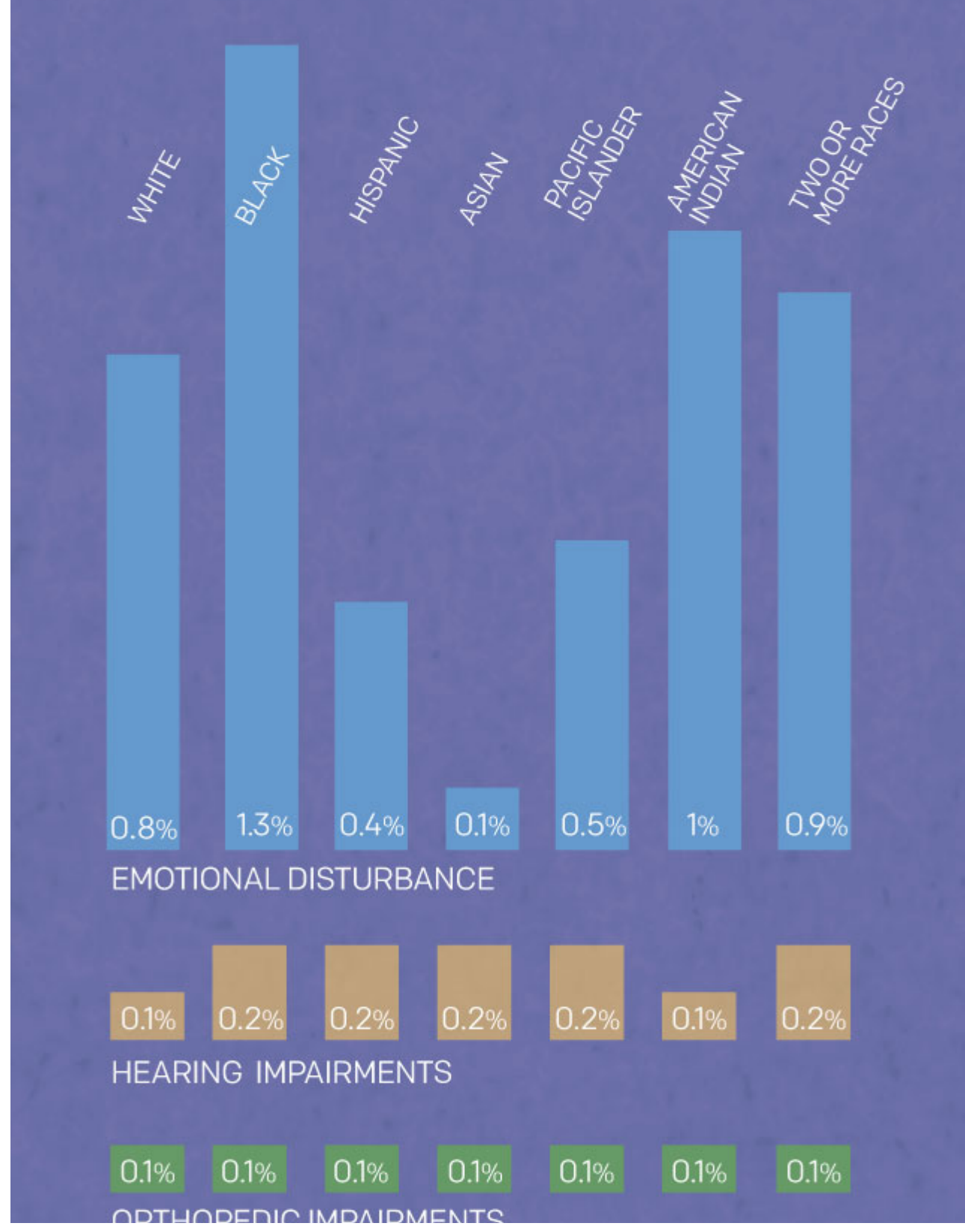an inability to maintain satisfactory relationships with peers and teachers;

general pervasive mood of unhappiness or depression;

tendency to develop physical symptoms of fear associated with personal or school problems.

WHO GETS LABELED WITH A DISABILITY?

While the percentage of students served for physical

disabilities such as hearing impairments or orthopedic impairments tend to be distributed evenly across racial groups, subjective labels like "emotional disturbance" are applied with more racial disparity.

WHITE   BLACK   HISPANIC   ASIAN   PACIFIC ISLANDER   AMERICAN INDIAN   TWO OR MORE RACES

| 0.8% | 1.3% | 0.4% | 0.1% | 0.5% | 1% | 0.9% |

EMOTIONAL DISTURBANCE

| 0.1% | 0.2% | 0.2% | 0.2% | 0.2% | 0.1% | 0.2% |

HEARING IMPAIRMENTS

| 0.1% | 0.1% | 0.1% | 0.1% | 0.1% | 0.1% | 0.1% |

ORTHOPEDIC IMPAIRMENTS
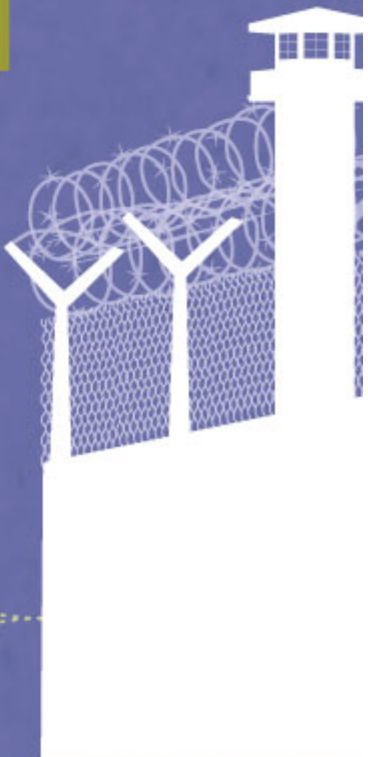
ORTHOPEDIC IMPAIRMENTS

0.1% 0.1%   0.1% 0.1% 0.1%

VISUAL IMPAIRMENTS

DISABILITY & INCARCERATION

KIDS WITH DISABILITIES

Are entering the juvenile justice system at a rate **5 times** higher than
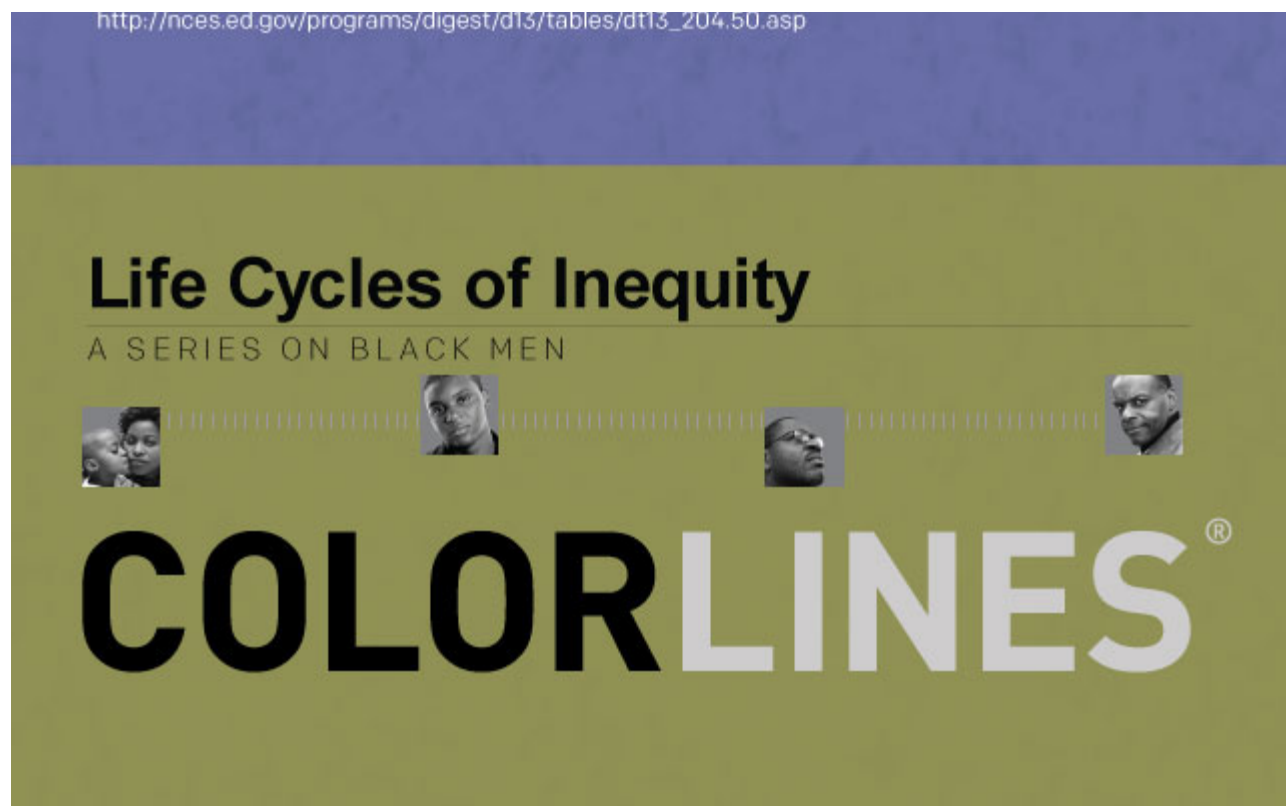
YOUTH IN THE GENERAL POPULATION

SOURCES

WHAT IS A DISABILITY?
http://idea.ed.gov/explore/view/p/,root,regs,300,A,300%252E8,c,4,i,

DISABILITY AND INCARCERATION?
http://ies.ed.gov/ncser/pubs/20113004/pdf/20113004.pdf

WHO GETS LABELED WITH A DISABILITY?

Read this online at http://colorlines.com/archives/2014/05 /from_disability_to_criminality.html

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Disablement, Prison, and Historical Segregation

by Jean Stewart and Marta Russell topics: Incarceration , Inequality , Political Economy , Race

The story of disablement and the prison industrial complex must begin with a trail of telling numbers: a disproportionate number of persons incarcerated in U.S. prisons and jails are disabled. Though Census Bureau data suggest that disabled persons represent roughly one-fifth of the total population, prevalence of disability among prisoners is startlingly higher, for reasons we will examine later. While no reliable cross- disability demographics have been compiled nationwide, numerous studies now enable us to make educated estimates regarding the incidence of various disability categories among incarcerated persons. Hearing loss, for example, is estimated to occur in 30 percent of the prison population, while estimates of the prevalence of mental retardation among prisoners range from 3 to 9.5 percent.

Rates of learning disability are spectacularly high among prisoners; in studies conducted among incarcerated juveniles, learning disabilities have been estimated to occur in up to 55 percent of youth nationwide; in one single-state study, 70 percent of youth qualified for special education. As for mental disabilities, in California anywhere from one-sixth to one-fourth of prisoners are believed to have diagnosable "serious mental disorders." Most stunning of all is a four-state study which examined juveniles imprisoned for capital offenses; virtually 100 percent of those studied were multiply disabled (neurological impairment, psychiatric illness, cognitive deficits), having suffered serious central nervous system injuries resulting from extreme physical and sexual abuse since early childhood.[1]

Why are so many prisoners in the United States disabled? Genetic determinists like to attribute the high prevalence of disability among prisoners to inherited deficiencies. For instance, James Watson of Cold Spring Harbor Laboratory holds that "we perhaps most realistically should see [a person's handicap] as the major origin of asocial behavior that has among its many bad consequences the breeding of criminal violence."[2] In opposition to this view, we propose the alternative approach forged by Marx: a material analysis of the economic and social forces of capitalism.

The structure of capitalist America plays a central role in the life of any group, including that of people with disabilities. Given the historic segregation of disabled persons not only from American society but from the accumulation process, disabled people living in the so-called free world have a grim commonality with their disabled compatriots behind bars. Institutions in general, including prisons, have functioned to support the accumulation of capital and the social control of surplus population, including the reserve army of unemployed left adrift by an economic system which dictates that large numbers of workers must be unemployed.

The prison population is not a cross-section of America; prisoners are poorer and considerably less likely to be employed than the rest of the population, and poverty in America is inevitably linked to a higher prevalence of disability. Neither quality health care, nor safe, adequate housing, nor nutritious food has been available to poor people. Environmental racism, the siting of toxic waste dumps and other poison-emitting industries in low-income, mostly non-white neighborhoods, has a devastating impact: not only are poor children exposed to lead and other toxins, resulting in high rates of developmental and learning disabilities; they also drink poisoned water and breathe poisoned air, leading to extreme prevalence of asthma and other respiratory illnesses and cancers. Poor people often live in neighborhoods plagued by

drug and alcohol abuse, leading to physical and psychological damage, including fetal alcohol syndrome, and marked by violent crime, leading to spinal cord injury, traumatic brain injury, and other disabilities.

As Christian Parenti explains in *Lockdown America*, capitalism, the creator of poverty, simultaneously needs and is threatened by the poor. In order to manage and contain its surplus populations and poorest classes, American capitalism has developed paramilitary forms of segregation, containment, and repression.3 Not coincidentally, it has created the social condition which we are calling "disablement" by excluding disabled persons from full participation in society through segregation, containment, and repression. It is this theory of disablement which we intend to explore here.

Historical Segregation and Social Control

Let us not be lulled into thinking that disabled persons living outside of prisons have autonomous lives. Institutional life, whether in a prison, hospital, mental institution, nursing home, or segregated "school" (and many receive no schooling), has been the forced historical reality, not the exception, for disabled persons.

Unlike race or gender, disablement is not generally thought of as the outcome of capitalist social power relations; rather, it tends to be viewed as a matter for medicine to cure or control. Our medical and social welfare institutions have historically held disablement to be an individual problem (a personal tragedy). They blame a disabled person's inability to participate fully in the economic life of our society on their physiological, anatomical, or mental limitations rather than on economic or social forces.

Disability activists and theorists, however, have laid a materialist groundwork for understanding disability oppression. If we trace how work evolved under capitalism, we can observe its effects on the disabled population. While one cannot claim that working-age disabled persons in pre-capitalist societies had achieved full integration and economic well-being, many occupied a niche in small workshops and family-based production, where they could contribute according to their ability. Economic historians Karl Polanyi and E. P. Thompson point out that early capitalism required a major shift in both the social organization of work and the concept of human labor. As human beings were gathered into the "dark satanic mills" to accomplish the sacred task of capital accumulation, circumstances arose which became barriers to disabled people's survival. Nondisabled workers had value because, as bosses pushed them to produce at an accelerating pace, they generated higher profits. But as work required increasingly precise mechanical movements of the body repeated in quick succession, disabled individuals were less capable of performing the tasks required of factory workers, and thus were viewed as of lesser value. Newly enforced factory discipline, time-keeping, and production norms replaced the slower, more self-determined and flexible work pattern into which many disabled persons had been integrated. Disabled workers were increasingly excluded from paid employment on the grounds that they were unable to keep pace with the new, mechanized, factory-based production system.4

Thus "the operation of the labour market in the nineteenth century effectively depressed handicapped people of all kinds to the bottom of the market."5 Industrial capitalism commodified the human body, creating both a class of proletarians and a class of "disabled" whose bodies did not conform to the standard worker physique and whose labor-power was effectively ignored. Over time, as disabled persons came to be regarded as a social problem, it became justifiable to remove individuals with impairments from mainstream life and segregate them in a variety of institutions, including workhouses, asylums, prisons, colonies, and special schools.

At the same time as it has marginalized and segregated disabled people in institutions, industrial capitalism, in its grinding push toward productivity at any cost, has caused disabling accidents and conditions to occur at an unprecedented rate. Viewed in this light, black lung, brown lung, asbestosis, and a host of other deadly illnesses are the direct offspring of capitalism, along with a chilling litany of incidents

in which factory workers have been paralyzed, burned, blinded, deafened, lost limbs, lost physical or mental function, or have otherwise been rendered disabled. Today, Repetitive Strain Injury debilitates hundreds of thousands of mostly high-tech workers, accounting for 66 percent of all reported work-related illnesses in 1999.

While capitalism shunted disabled persons out of the worker pool and into institutions, the medical industry pathologized traits such as blindness, deafness, and physical and mental impairments that have naturally appeared in the human race throughout history. In the Foucaultian sense, medicalization and institutionalization became means of social control, relegating disabled persons to isolation and exclusion from society; the combination met capitalism's need for discipline and control. Michael Oliver explains:

[the institution] is repressive in that all those who either cannot or will not conform to the norms and discipline of capitalist society can be removed from it. It is ideological in that it stands as a visible monument for all those who currently conform but may not continue to do so: if you do not behave, the institution awaits you.6

Institutions of all descriptions thus became formidable, formalized containment devices. It is now the disability rights movement's primary revolutionary goal to reverse this trend.

The impact on disabled people of this kind of segregation has been profound. They are the least likely to be employed, the most likely to be impoverished and undereducated. Only a third of working-age disabled individuals are currently employed, compared to more than 80 percent of the nondisabled population. One-third (34 percent) of adults with disabilities live in households with an annual income of less than $15,000, compared to 12 percent of those without disabilities—a 22-point gap which has remained virtually constant since 1986. Disabled persons are twice as likely not to finish high school (22 percent versus 9 percent). A disproportionate number of disabled persons report having inadequate access to health care (28 percent versus 12 percent) or transportation (30 percent versus 10 percent).7 Of course, one must acknowledge that disabled people live on the economic margins of all societies throughout the world, not merely in capitalist countries. But nowhere else are we witness to the jarring disconnect between a society's vast wealth and its refusal to provide more than the barest means of survival for its most vulnerable citizens.

Capitalist Accumulation and Unemployment

Social control does not tell the complete story of disabled peoples' segregation and ensuing institutionalization. By placing the focus on "cure," and by segregating "incurables" into the administrative category of "disabled," the medical industry bolstered capitalist business interests and shoved less exploitable workers with impairments, or those who obstructed capital accumulation, out of the workforce.

Ten years after passage of the Americans with Disabilities Act (ADA), the unemployment rate of disabled people has barely budged from its chronic 65–71 percent. This appalling figure remains steadfast despite a growing U.S. economy, a low aggregate national official unemployment rate (4.2 percent), advances in technology which have expanded the range of jobs disabled workers can perform, and a poll showing that over 70 percent of working-age disabled persons say they would prefer to have a job. According to a recent study, while many Americans reaped higher incomes from an economy that created a record number of new jobs during seven years of continuous economic growth (1992-1998), the employment rates of disabled men and women continued to fall.8

When Congress enacted the ADA, it specified three major goals: elimination of arbitrary barriers faced by disabled persons; an end to inequality of opportunity; and a reduction in unnecessary dependency and unrealized productivity. However, by failing to acknowledge that capitalism produces disablement, the ADA has not fully confronted economic discrimination. Whether their fears are real or perceived, U.S. employers express concerns about increased costs incurred by providing accommodations (e.g., interpreters,

environmental modifications), anticipate extra administration costs when hiring nonstandard workers, and speculate that a disabled employee may increase worker's compensation costs in the future. If they provide health care insurance at all, employers anticipate elevated premium costs for disabled workers. Insurers and managed care health networks often exempt pre-existing conditions from coverage or make other coverage exclusions based on chronic conditions, charging extremely high premiums for the person with a history of such health care needs. Employers, in turn, tend to look for ways to avoid providing coverage to cut costs. In addition, employers characteristically assume that they will encounter increased liability and lowered productivity from a disabled worker.

There is a strong correlation between disability onset and employer firings. Data from the Equal Employment Opportunity Commission (EEOC), the agency responsible for monitoring employment discrimination under civil rights statutes, show that the most prevalent (53.7 percent) cause of complaints filed by disabled workers is involuntary termination upon disablement, while another third involve an employer's failure to provide reasonable accommodation.

Not surprisingly, U.S. courts traditionally support business interests. Studies show that in the first eight years after passage of the ADA, defendant-employers prevailed in more than 93 percent of reported ADA employment discrimination cases decided at the trial court level. Comments Ohio State University Law professor Ruth Colker: "Only prisoner rights cases fare as poorly."[9]

Sentenced to Hard Labor

At the same time that U.S. capitalists close their doors to disabled workers, their drive to maximize profits in today's global economy leads them to abandon even their non-disabled employees, relocating factories overseas where wages are as little as twenty cents per hour, child labor is legal, and workers are not provided benefits or health care. They have also rediscovered that they do not have to go so far afield.

If relocation of factories to developing countries has produced lavish profits for the capitalist class, little can compare to the windfall generated in recent years by an even more lucrative worker pool: prison labor. Not only are prisons posited as a primary solution to the country's social problems, but prisons are among the fastest-growing industries in the United States. Workers earn as little as twenty-two cents per hour, and companies avoid the added costs of shipping and infrastructure enhancement required when they operate in poorer countries. Not coincidentally, Occupational Safety and Health Administration laws do not apply to the prison industry, with the result that materials used in prison manufacturing are often toxic and dangerous when handled without adequate protection. For example, urethane foam used in furniture production by California's Prison Industry Authority at Tehachapi Prison is cut to size in unventilated shops, posing a potentially lethal health threat to prisoners. When the foam is cut with power saws, tiny particles are dispersed into the air. Trapped inside human lungs, these particles are carcinogenic, causing a condition similar to asbestosis. Urethane foam also produces a lethal gas if accidentally ignited.

In a grotesque sidebar to this story, state agencies, schools, hospitals, and libraries are forced under California law to buy these prison-made chairs and couches, despite the foam's clearly printed warning. Though the California Furniture Association does not approve the use of this foam in furniture, the Prison Industry Authority ignores the danger.

What we have is a billion-dollar manufacturing industry that legally utilizes slave labor, has little overhead, is unregulated by state and federal workplace safety or labor laws, provides no health insurance or benefits and no sick pay for its employees, includes hazardous materials in the construction of its products, forces customers to buy those products under penalty of law, and prohibits its workers from organizing. "There has not been a larger pool of 'free labor' since the end of the Civil War."[10]

Commodification and Institutional Power

Although disabled people have been excluded from the labor force through economic discrimination and compulsory unemployment, one should not assume that these millions have been ignored as a source of profits. The "unproductive" ones, those who do not provide an able body to create surplus value as laborers, shore up U.S. capitalism by other means. By clever capitalist alchemy, disablement has been spun into big business. One corporate approach to nonproductivity, institutionalization in a nursing home, evolved from the cold realization that financing "Medicaid funds 60 percent, Medicare 15 percent, private insurance 25 percent" guaranteed a source of entrepreneurial revenue. When a single impaired body generates $30,000- $82,000 in annual revenues, Wall Street brokers count that body as an asset which contributes to, for example, a nursing home chain's net worth. Though transfer to nursing homes and similar institutions is almost always involuntary, and though abuse and violation of rights within such facilities is a national scandal, it is a blunt economic fact that, from the point of view of the capitalist "care" industry, disabled people are worth more to the Gross Domestic Product when occupying institutional "beds" than they are in their own homes.11

Such commercial enterprises are staffed by a hierarchy of professionals who depend upon the class of disabled persons to survive. Oliver writes:

[under capitalism] the production of the category of disability is no different from the production of motor cars or hamburgers. Each has an industry, whether it be the car, fast food, or human service industry. Each industry has a workforce which has a vested interest in producing their [sic] product in particular ways and in exerting as much control over the process of production as possible.12

This observation is critical to disabled people's liberation and will be revisited later. Who controls the services, what those services are and where they are rendered are major issues in disabled people's struggle for self-determination, a struggle which has become increasingly formidable as government and corporations dismantle the social contract.

The Neoliberal Shift, Deinstitutionalization, and Incarceration

To better understand the relationship between disability and prison, it is instructive to focus on the treatment of those who are mentally ill.13 In the second half of the twentieth century, the dominance of the mental health institution began to decline as the capitalist economy underwent restructuring. Economic stagnation and low profits, the fiscal crisis of the seventies, were met with Reaganomics, i.e., tax cuts for corporations and the wealthy, an attack on labor, deregulation of health and safety regulations and cuts in state spending on education, welfare, and social programs, including those institutions housing people with mental illnesses.

Deinstitutionalization, as it related to those who had been labeled mentally ill, was a government policy change driven by cost-cutting motives. Spending by the fifty states on treatment for people with mental illness, for instance, was lower by a third in the nineties than it was in the fifties; fewer than half of Americans diagnosed with schizophrenia receive adequate services today. When the awful snake pits of neglect and abuse we called "mental institutions" were closed, necessary new structures and solutions, including community housing, employment services (a vital component for populations experiencing severe labor market discrimination), and other appropriate programs designed and run by disabled individuals themselves, were never put in place.

Instead, GOP revolutionaries of the 104th Congress, falsely blaming the deficit on the welfare state and entitlements, attacked the social safety net. The 1990's crackdown on federal disability and welfare benefits and state reductions to General Relief and Medicaid further expanded the scope of damage to deinstitutionalized people who had been diagnosed with mental illness, many of whom found themselves destitute the moment they were discharged from the hospitals.

Because the states had abandoned their social contract with deinstitutionalized people labeled mentally ill, many were left stranded on the streets, caught up in the revolving door between homelessness and prison. At present, an overwhelming number of jail inmates with mental illness were homeless. For instance, of the approximately 2,850 mentally ill people in New York City jails on any given day in 1996, 43 percent were homeless. The vast majority were not violent or dangerous; they have been jailed for petty theft, disturbing the peace, and other "crimes" directly related to their illness. Increasingly, the judicial system punishes such people for their "quality of life" misdemeanors by slapping them with jail sentences—670,000 of them in 1996. At any given moment, 40 percent of all Americans with serious mental illness are estimated to be in jail or prison, comprising from 10 to 30 percent of all inmates. The Center on Crime, Communities & Culture concludes that in many jurisdictions, jails have become the primary "treatment" provider for poor people with mental illnesses.[14]

This "criminalization of mental illness" has its roots in the U.S. capitalist health care system and the growth of the prison industry. The great majority of "mentally ill" people in New York jails and prisons, for instance, are Medicaid recipients or have no insurance at all. To qualify for Medicaid, low-income individuals must be extremely debilitated and indigent (which many achieve by spending down savings), and they must stay indigent.

Adding insult to injury, mental health parity does not exist in the private U.S. insurance system. For instance, private long-term disability plans, most of them employer-sponsored, provide benefits to eligible recipients with "physical disorders" through age sixty-five, while they impose duration limits of twenty-four months or less on benefits to eligible recipients with "mental disorders." In defending its refusal to provide mental health parity, the insurance industry claims the extra coverage would place a demand on the for-profit system which would cause everyone's premiums to skyrocket. In order to protect its profit margin, the corporate health care industry denies this segment of the population treatment and services.

The rise of managed care, now the dominant paradigm among hospitals and physicians, has also had a debilitating effect. In the name of cost containment, payment mechanisms have shifted; hospitals and doctors are now paid a flat fee, instead of receiving payment for individual services rendered. Because of financial incentives for physicians and hospitals to keep costs low, people who have been hospitalized for "mental illness" are often discharged in three weeks, ready or not, without a discharge plan that would provide them with crucial community support.

People with so-called mental illnesses are generally deemed to have little or no production value. Their unemployment rate is the highest among the disabled population at 80 percent, and disproportionately high within the incarcerated population. Perhaps the term "social junk," as coined by criminologist Steven Spitzer, best describes how society views this cast-off segment of the population. People labeled "mentally ill" experience harsh discrimination in many arenas, among them housing, employment, and health insurance. Increasingly they have become a part of what Christian Parenti calls "a growing stratum of ? surplus people' [who, because they are not] being efficiently used by the economy must instead be controlled and contained and, in a very limited way, rendered economically useful as raw material for a growing corrections complex." Thus the old "snake pit" mental institution is being replaced with yet another institution, the prison, where incarcerated "social wreckage" contributes to the GDP by supporting thousands of persons associated with expanding and maintaining the prison industry.

Mental health advocacy groups rightly point out that people with mental illness rarely belong in prison. Jail diversion and discharge planning, they say, are key to stopping the "revolving door" of repeated hospitalizations and incarcerations. They recommend ongoing community treatment and support services, all grossly underfunded now, to mend the broken system.

The psychiatric social change movement, comprised of survivors of the mental health industry, is wary of solutions that may lead to forced hospitalization, involuntary psychiatric drugging (psychiatric medicine is

not a science and damage is often done by inappropriate drugs), and forced electroshock, all of which have been a part of the corporate psychiatric model. The World Bank now has a "mental health division" to promote corporate psychiatry globally! In thirty-seven states, people living in their own homes can be court-ordered to take psychiatric drugs even though many experience toxic reactions to such treatment. Six states have "at- home" drug deliveries. The shattered mental-health system has largely depended upon one or another form of incarceration and forced treatment, whether in hospitals or prisons. In their efforts to end the involuntary imprisonment of so-called mentally ill persons, grassroots social change groups are concerned that one destructive institution not be replaced with another. The focus must be on human rights (including the right to refuse treatment), empowerment, and alternatives such as community and peer support.

Oppression Behind Bars

We have shown that American capitalism, in its failure to incorporate disabled people into its social fabric, instead shunts them into prisons and other institutions. Not surprisingly, once behind bars, prisoners with disabilities face even greater abuse and discrimination than they had encountered on the outside. For example, throughout the United States, guards are known to confiscate from inmates with disabilities whatever will be most acutely missed: wheelchairs, walkers, crutches, braces, hearing aids, glasses, catheters, egg crates (special mattresses designed to prevent skin breakdown and aid circulation), and medications.[15] Prisoners who require personal care or assistance—for example, quadriplegic inmates who need help with eating, dressing, bathing, etc.—are simply ignored; they go without meals and are forced to urinate on themselves in the absence of bathroom assistance. Because of architectural barriers, physically disabled inmates are unable to access dining halls, libraries, work and recreational areas, and visiting rooms, not to mention the toilets, sinks, and beds in their own cells. Blind prisoners are unable to read their own mail or research their cases in the prison law library because they are not provided with readers or taped/Brailled materials. Deaf prisoners are denied interpreters, making it impossible for them to participate in work programs, counseling, alcohol and substance abuse programs, medical appointments, and their own parole and disciplinary hearings. Disabled prisoners are routinely denied enrollment in work furlough programs, sometimes significantly lengthening their periods of incarceration.

All of the above are violations of the Americans with Disabilities Act which, under the Supreme Court's 1998 ruling in Yeskey (*Pennsylvania Department of Corrections et al. v. Ronald R. Yeskey*), applies to state prisons. In addition, psychological abuse of disabled prisoners by guards—for example, the moving-around of furniture in the cell of a blind prisoner, or verbal taunts over a loudspeaker —have been documented in prison after prison throughout the country. Also rampant is medical abuse; across the United States, prisoners with treatable disabling conditions die as a result of medical neglect. Both psychological and medical abuse are clear violations not only of the Eighth Amendment to the Constitution (injunction against cruel and unusual punishment) but of various international human rights statutes.

It is ironic that the institution which most dramatically exemplifies American society's failure to humanize disability not only cranks out furniture and license plates but manufactures disability as well. The harshness of prison life disables people. Inadequate or absent medical care, poor nutrition, violence, and extremes of heat, cold, and noise inside prison, not to mention the lack of sensory, emotional, intellectual, and physical stimuli, all lead directly to acute or chronic physical and psychological disabilities.

Prison overcrowding accelerates the disabling process. Humans who are packed into spaces designed for one-third the number of people actually residing in them are bound to find themselves in more frequent, and more disabling, violent confrontations. Guards working in such environments resort to violence more readily. Overcrowded prisons provide an even poorer standard of physical and mental health care, and almost universally produce depression, sometimes acute, as well as a panoply of other immobilizing psychological disorders. Additionally, they provide a ripe environment for the flourishing of gangs and gang

violence, resulting in permanent injuries.

Disability is also a byproduct of the correctional system's obsessive infatuation with security and control. Isolation units, sensory deprivation cells, and other instruments of torture such as cattle prods and stun guns generate mental breakdowns and exacerbate pre-existing illness.

The prison labor industry, as has been mentioned earlier, is entirely unregulated by workplace safety and health standards, resulting in dangerous work environments. AIDS and Hepatitis C epidemics, unchecked by even the most basic, humane medical intervention, have wrought havoc on the prison population. Finally, as we lock up prisoners for longer and longer periods due to mandatory minimum sentencing laws, the prison population is aging; with age comes disability.

Stopping the Capitalist Juggernaut

In twenty-first century America, the prison industrial complex is a multi-billion-dollar capitalist juggernaut, devouring everything in its path. The United States spends far more on corrections than it spends on higher education, locking up more than 700 people per 100,000 population, while most "enlightened" countries incarcerate fewer than one hundred citizens per one hundred thousand. In some American inner cities, the rate of incarceration is twenty-five hundred to three thousand per one hundred thousand. In 1995, the prison population topped one million; since then it has grown at a rate of 8.5 percent a year.

Syndicated columnist Anthony Lewis, commenting on proposed legislation that would give the states $10.5 billion to build more prisons, observed: "Once the states have made the investments in such prisons, there will be an inevitable urge to fill them. Sentences will tend to get longer." U.S. District Judge Wilkie Ferguson Jr. continues this line of thought:

Corrections facilities are being contracted to private corporations for both construction and operation. The private companies are required to operate the prisons at 7 percent below government cost estimates. These firms encourage purchase of their stock by projecting growth in earnings, to be paid mostly from tax dollars. Their rosy projections assume increased incarcerations. Companies that do business with prisons also foresee growth. So there is already a powerful profit incentive in keeping prisons at maximum occupancy.16

With such economic forces as these at work, we should not be surprised that prisons are overcrowded, that mandatory minimum sentences are enjoying unprecedented judicial popularity, and that disabled inmates are dying of abuse and neglect while their complaints fail to register even a blip on the capitalists' Richter Scale.

Clearly a well coordinated, activist, collective, and social-change oriented response is required. Those who are concerned about disability rights, civil rights, prisoners' rights, and human rights must join together and mobilize to put pressure on the prison system. Concomitantly, we must call for a drastic social and economic restructuring of the organization of work. We must create a social order based on equality, an order that does not punish those who cannot work, that does not make "work" the defining measure of our worth, and that offers counter values to the prevailing productionism which only oppresses us all.

Notes

[A complete set of notes to this article may be obtained from the *Monthly Review* office. Please contact the assistant editor or using our contact form

1. Dorothy Otnow Lewis, "Neuropsychiatric, Psychoeducational, and Family Characteristics of 14 Juveniles Condemned to Death in the United States," *American Journal of Psychiatry* 145, no. 5 (May 1988), 584-89.

2. James D. Watson, "President's Essay," Cold Springs Harbor Laboratory 1996 Annual Report, 14.

3. Christian Parenti, *Lockdown America* (London: Verso, 1999), 238.

4. . See Vic Finkelstein, *Attitudes and Disabled People: Issues for Discussion* (New York: World Rehabilitation Fund, 1980); Michael Oliver, *The Politics of Disablement* (New York: St. Martin's Press, 1990); Marta Russell, *Beyond Ramps* (Maine: Common Courage Press, 1998); and Joanna Ryan and Frank Thomas, *The Politics of Mental Handicap* (New York: Penguin, 1980).

5. Pauline Morris, *Put Away* (London: Routledge & Kegan Paul, 1969).

6. Michael Oliver in R. Flynn and R. Lemay, eds., *A Quarter Century of Normalisation and Social Role Valorization*: (Ottawa: University of Ottawa Press, 1999).

7. Louis Harris, *The 2000 National Organization on Disabilities/Harris Survey of Americans with Disabilities* (New York: Louis Harris & Associates, 2000). See also the 1998 Report.

8. Peter Budetti, et. al., *Ensuring Health and Security for an Aging Workforce* (Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, 2001).

9. Ruth Colker, "The Americans with Disabilities Act: A Windfall for Defendants," *Harvard Civil Rights—Civil Liberties Law Review* 34(1999), 99, 100.

10. "When Punishment is the Crime: The Privatization of Prisons," *Out of Time* 31 (Feb. 1996), 3.

11. 1.9 million disabled Americans are incarcerated in nursing homes; 150,257 children and adults are locked down in mental institutions; 77,618 children and adults are hidden away in state-owned institutions for people with mental retardation and other developmental disabilities. See Russell, *op. cit*. ,96-108.

12. See Oliver, note 6 above.

13. The authors wish to credit the psychiatric survivors' movement for a large body of literature examining America's social policies with regard to people who have been labeled "mentally ill." Among its sharpest commentary has been the movement's critique of language; analysts point out that such terms as "the mentally ill" are highly charged, pejorative cultural constructs. They observe that such labels have been assigned to them by an entrenched power structure, relying for its authority on the DSM—the Diagnostic & Statistical Manual of Mental Disorders—a reference book that has repeatedly and justly been challenged for the subjectivity and bigotry underlying many of its socially constructed "diagnoses." Psychiatric survivors point out that throughout history, individuals who have been identified by the dominant class as "mentally ill" have in many cases been iconoclasts and mavericks whose behavior has been provoked by social injustice. In a paper which examines the situation of people who have been incarcerated—whether in prisons, nursing homes, or mental institutions—we particularly want to avoid the assumption that those labels which have been used to justify incarceration are appropriate or just. Readers are referred to Support Coalition International of Eugene, OR: www.MindFreedom.org and to its newsletter, *Dendron News*.

14. Heather Barr, "Prisons and Jails" *Hospitals of Last Resort*: The Need for Diversion and Discharge Planning for Incarcerated People with Mental Illnesses in New York," A research brief from the Center on Crime, Communities & Culture, 1999.

15. Jean Stewart, "Life, Death & Disability Behind Bars," *New Mobility* 9, (June 1998). See also Jean Stewart, "Inside Abuse: Disability Oppression Behind Bars," *The Disability Rag* 15, (Nov./Dec. 1994).

16. U.S. District Judge Wilkie Ferguson Jr., "Prisons: An American Growth Industry, *" Miami Herald*, April 9, 1995.

Sins Invalid

An Unshamed Claim to Beauty in the Face of Invisibility

Sins Invalid is a performance project that incubates and celebrates artists with disabilities, centralizing artists of color and queer and gender-variant artists as communities who have been historically marginalized. Our performance work explores the themes of sexuality, embodiment, and the disabled body.

Conceived and led by disabled people of color, we develop and present cutting-edge work where dominant paradigms of "normal" and "sexy" are challenged, offering instead a vision of beauty and sexuality inclusive of all individuals and communities.

We define disability broadly to include people with physical impairments, people who belong to a sensory minority, people with emotional disabilities, people with cognitive challenges, and those with chronic/severe illness.

We understand the experience of disability to occur within any and all walks of life, with deeply felt connections to all communities impacted by the medicalization of their bodies, including trans, gender-variant, and intersex people, and others whose bodies do not conform to our cultures' notions of "normal" or "functional."

Sins Invalid recognizes that we will be liberated as whole beings –

– as disabled/as queer/as brown/as black/ as genderqueer/as female- or male-bodied – as we are for greater whole than partitioned. We recognize that our allies emerge from many communities and that demographic identity alone does not determine one's commitment to liberation.

Sins Invalid believes in social and economic justice for all people with disabilities – in lockdowns, in shelters, on the streets, visibly disabled, invisibly disabled, sensory minority, environmentally injured, psychiatric survivors – moving beyond individual legal rights to **collective human rights.**

Our stories, embedded in analysis, offer paths from identity politics to unity amongst all oppressed people, laying a foundation for a collective claim of liberation and beauty.

Our goals are to:

- Provide a supportive and politically engaged space for both emerging and established artists with disabilities to develop and present compelling works to a broad audience.

- Develop and present strong artistic work that explores sexuality and the non-normative body, integrating the full experiences of disabled artists who are also people of color and LGBTI, in order to represent all of our communities and challenge dominant misperceptions about people with disabilities.

- Promote leadership opportunities for people with disabilities within our communities and the broader social justice movement.

We do this by:

- Presenting multidisciplinary performances (including video, poetry, spoken word, music, drama, and dance) by people with disabilities for broad audiences in the San Francisco Bay Area and elsewhere.

- Organizing multidisciplinary performance workshops for community members with and without disabilities (e.g., poetry workshops, dance workshops, vocalization workshops).

- Offering political education workshops for organizations that share our commitment to social justice principles as a means of integrating analysis and action around disability, race, gender, and sexuality.