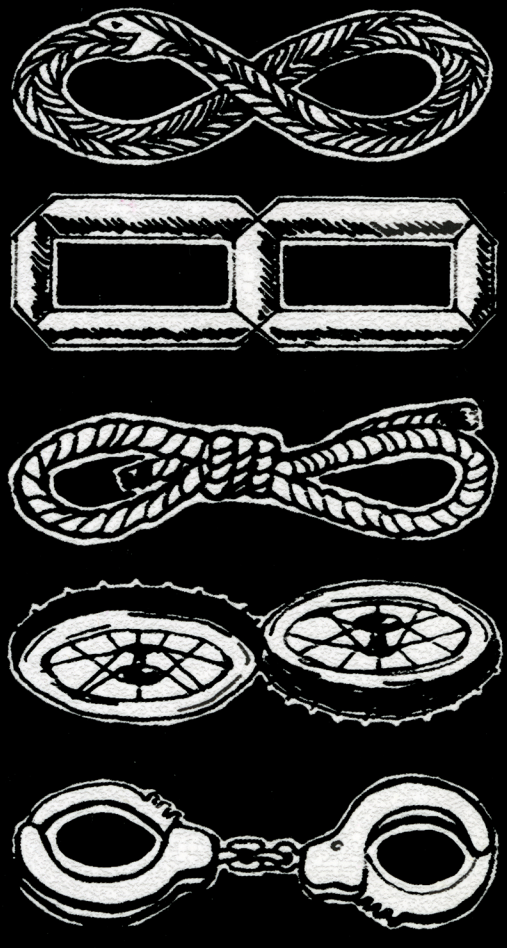
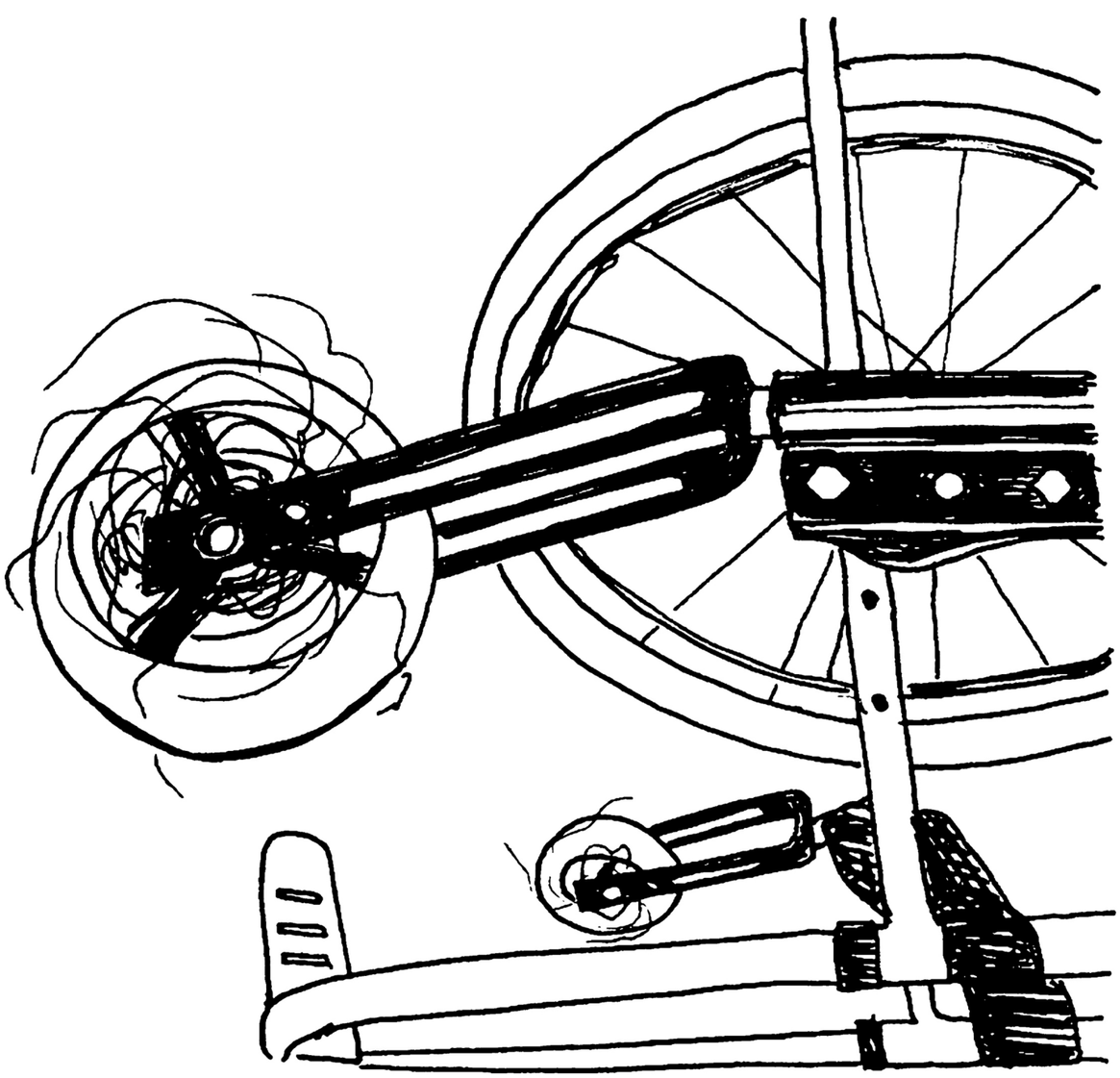
THE RING OF FIRE ANTHOLOGY



ET RUSSIAN



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seattle, WA 98101
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http://www.leftbankbooks.com
publishing@leftbankbooks.com

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THE RING OF FIRE ANTHOLOGY

BY
ET RUSSIAN

THANK YOU

I want to give sincere thanks for all the encouragement, love, editing feedback and support I received during the process of creating this book… To Left Bank Books Publishing for making this anthology possible, Mend My Dress Press for production work, The University of Washington Disability Studies 2013 Harlan Hahn Award for being able to complete the book and tour it, and the STAG Library writing residency for a creative space. To Tina McKim, Elizabeth Payne and Andy Allen for invaluable editing feedback, to Peta Pottinger for collaborating with me, to Annie Murphy, Leah Lakshmi Piepzna-Samarasinha and Eroyn Franklin for guidance regarding the ups and downs of the writing and publishing process, and to the loving support of my blood family and chosen family, without which this work would not be possible.

To Lisa Bufano, Ronald Takaki, Vic Chesnutt, and all the other incredible extended family members who are not with us anymore. To all of those who are still with us like my Sins Invalid family, the members of the Seattle Disability Justice Collective, the Seattle Coalition of Anti-Racist Whites, and my fellow Art Group members. To all of my friends who write and don't censor their creative ideas, and all the crips who get on stage and dance. And to some of my deepest, most profound creative and political influences including Freddie Perry, James Baldwin, Krip Hop, Suzan Lori-Parks, Anna Deavere Smith, Jean-Do Bauby, Octavia Butler, The Hernandez Brothers, Ursula K. LeGuin, Lynda Barry, Langston Hughes, Eli Clare, Patty Berne, Bob Flanagan, Yoko Ono, and Louise Bourgeois.

INTRODUCTION

At first I thought *it's too late to release this writing again.* The last issue of *Ring of Fire* released was in 1999. That was fifteen years ago. Then, I remembered that *Craphound* zine (an awesome clip art zine) came out with a new issue after eight years of not publishing, Aaron Cometbus is still doing *Cometbus* zine more than thirty years later, and Dolly Parton won a Grammy forty years into her career for her first bluegrass album. When I realized all that, I figured it wasn't too late for me to write a new issue of *Ring of Fire*. I have spent the last few years working on what I thought would be new issues of the zine. There was so much new material I was planning on a double issue release. Then, Left Bank Books Publishing approached me about publishing a *Ring of Fire* anthology and that's how this project got started. This anthology contains abridged versions of *Ring of Fire* zine issues 2 and 3, and more than half of the book is new material created in the last several years.

Acquiring a disability at age eighteen impressed upon me the idea that if I was ever going to go off of welfare benefits I would need a stable job that gave me medical coverage. Having artificial legs is like having a used car; they are always in the shop for repairs. Last year my legs cost $20,000. Going to school and becoming a Physical Therapist is what I did. It meant I could have job stability, work anywhere I want, and get benefits. Choosing this line of work meant I could work with other people like me, who were going through Rehab for whatever reason. Plus, I thought I would be good at the job.

A WRITER IN SCIENTIST'S CLOTHING

When I went to school to become a physical therapist my artistic and writing life had to be put on hold. That was really hard. Deciding to go the scientific route was intimidating. Taking Biology, Anatomy with human cadavers, Physics, Organic Chemistry, Biomechanics, and Genetics made me feel like my brain grew another half. I was raised as an art kid, super creative. My mom is an artist. I took oil painting, sculpting and watercolor classes instead of sports. But, I never learned how to approach a complex problem and break it down into manageable parts until I took Physics at the community college. As a feminist I had always been frustrated that my logical reasoning skills were not what I wanted them to be. Scientific writing in school (think lab reports, math problems and research papers) is supposed to be scientific, not creative. The process of learning to write that way, while it is a useful skill, also stifled my creative mind. When I am in a truly creative space I censor my ideas less, my thinking becomes more free and expressive and the things I make, the ideas I generate, reflect more of my instinctive creativity. Making creative work again has been hard, and scary and made me feel very alive. I believe creativity has a momentum to it. When my art life got put on hold my creative momentum completely died and I had to rebuild my creative life from nothing. It felt like learning to walk again. I am proud of myself for expanding my brain to think in new ways, and I also miss those years that I was not able to create. When they were happening I felt really distanced from the core of myself and that was very hard. But, at the same time the core of who I had been was changing.

When I first wrote *Ring of Fire* I was working out so much about my disability and my sexuality and gender. Looking back on what I wrote about my body and about ableism, I think that in a lot of ways I was writing to

an audience of people without disabilities. Trying to explain to them what I was going through so they could gain a deeper understanding. Really, I think that I was trying to explain it to myself and it just happened to be helpful to other people who were also new to disability as a concept.

BECOMING A HEALTHCARE PROVIDER

Besides the journey I took through school and finding work, another reason I didn't work on new material for *Ring of Fire* for a long time was because I wanted to write from a new perspective and I needed more time to do that. There is so much to say about the disability experience, about disability culture, about healthcare in this country and about what its like to live under the poverty line and on welfare. It's been seventeen years since I lost my legs. A long time spent living "the life." The first two years I worked at the hospital doing physical therapy were surprising emotional for me. I would leave work feeling so full and I could not understand why. I felt this pull to start writing about my work. I started keeping a work journal so I could try to tease apart what was I was experiencing. I realize now that I was witnessing a lot of other people's lives on an intimate level. I needed time to process it all. Some of it was joyous, but some it I had to grieve. Many chronically ill people and people with disabilities are isolated, living in poverty, and are very challenged in living the lives that they want. There is a lot of societal prejudice against disabled people, including internalized ableism that people struggle with. For years I had been on the receiving end of the health care system, going to my own appointments. Becoming a health care provider put me on the other side. I am now both a giver and a recipient of healthcare in this country, and these perspectives give me broad insight into the inner workings of our healthcare system.

DISABILITY JUSTICE

I see our cultural understanding of disability evolving. In the past six years or so, the concept of disability justice has emerged, and this work has been extremely influential for me. Disability justice, as a movement, is being envisioned primarily by disabled people of color and white people who are working for racial justice; it understands ability and identity in the context of connectedness to other identities and movements. Homelessness, poverty, access to affordable healthcare, housing and transportation are not just issues for disabled people, these issues affect all people. For disabled people of color and immigrants the inequalities are compounded. Unfortunately, racism is still unchecked in many disability spaces. The traditional disability rights movement, which has been a largely single-issue movement, is still dominated by the agendas of white people. In order to change this dynamic white disabled people need to be working towards racial justice, on a personal level and a societal level. Developing my understanding as a white anti-racist person has been a very humbling and ongoing process of self-examination. In working on *Ring of Fire* I made an intentional shift to focus on the work of other people creating cultural change because it takes all of our perspectives to build a culture where everyone can flourish.

WRITING INFLUENCES

The process of writing can be a lonely one. Working on this book has been very lonely at times. But, it has also felt the opposite of that. I like to interview people for two reasons, one is that I'm a social person and I want to feel connected, two is that I am a documentarian at heart and I believe that our stories, ideas and culture are the legacy we leave to the future.

My ideas have also very much been grown and influenced by the people I have known. Many of the people in this collection are close friends, some very old friends. I started writing *Ring of Fire* in 1996. Some of my biggest writing influences at that time were my favorite zines such as *Bamboo Girl*, and *Fat Girl*, and of course, pacific northwest punk culture and riot grrl were extremely influential. My current writing and art for the book draws from my involvement in recent years with the disability justice movement and organizations like Sins Invalid and the Seattle Disability Justice Collective.

I think I chose to write my essay series "Growing a New Lens" because I wanted to surround myself with guardian angels, the spirits of people who could help me grow and finish this project. I have a very spiritual approach to writing. I was raised by humble, salt-of-the-earth parents who tell funny stories, but would never think of publishing them. In order to summon the self-esteem and belief in myself that I could and should publish, I've had to go to some deep spiritual places. When I feel I'm alone that is hard to do. But, when I feel the presence of the people I'm writing about surrounding me, even the people I don't know like Yayoi Kusama, Rick Allen, Homer Avila, and Chuck Close, I feel comforted, like they are quietly encouraging me to write or to pick up my drawing pen.

THIS BOOK IS VERY HUMBLING FOR ME BECAUSE

I am reprinting things I wrote when I was eighteen. In many ways it is like a timeline of my evolving thought process, as well as healing process around my disability. In some ways I see myself age on these pages. The zine material in this anthology is abridged (not complete) for a few reasons. One is I edited out content that didn't feel relevant anymore, mostly because it felt really dated, or in some instances, hurtful. Another is I edited out the articles from the original zines that I reprinted without permission from newspapers and books on the topics of science, technology, sex and disability. It's too bad, because the critical responses I wrote to those articles were interesting, for example research to reattach missing limbs and the pros and cons of a surgery like that.

RING OF FIRE

ISSUE 2



THIS ZINE PROMOTES QUEER SEX, GENDERFUCK, AND THE ADVANCEMENT OF AMPUTEES EVERYWHERE.

SO, YO !!!

butt-fuck till you die.

thigh-high stockings are my favorite

On September 14, 1996 I was trainhopping for the first time with some friends and when I jumped off the train it ran over my legs and they were both amputated below the knee. It's been six months now and I'm dealing pretty well but a lot has changed: I'm 19 and I'm disabled. I have a wheelchair and a disabled parking pass and everything. It's really a freaky thing to deal with, but I figure the only way to make it through is to be a tough ass bitch. In the words of Lynda Barry: FREAK OR BE FREAKED!! I'm determined to make being disabled an erotic thing so I hope this zine gets you hot.

thanx for reading, HELLERY HOMOSEX MARCH 1997

Send mail to my new p.o. box. [redacted]

[redacted]

QUEERCRIPS ROCK MY ASS OFF

PLEASE give yr post-age stamps so I can re-use them

RING OF FIRE
PO BOX 23036
Seattle, WA
98102-0336



GUESS WHICH ONE OF THESE PERSONAL ADS WAS MINE

IV BLONDIE

WHEN ORDERING A ZINE, PLEASE SEND ONE DOLLAR IF YOU CAN, IF YOU HAVE NO $, I'LL SEND U ONE ANYWAY

FOOT LICKING

A few months before I lost my feet I had a most amazing sexual experience. My partner laid me down on my back, kissing me down my legs to my feet. Slowly she took a foot to her mouth, kissing each and every part of it gently and with much attention. My heel, my arch. She sucked each toe individually, over and over. Like there was all the time in the world for it. Twenty minutes on one foot. I lay there with my eyes closed, feeling everything in total bliss. As a pisces my sign is associated with the feet. I always loved my feet. LOVED THEM. I massaged them, lotioned them, washed them, warmed them, painted them, clipped them, kissed them. I took quite good care of them. But I had never met anyone else that treated them

SOMEBODY TOLD ME I COULDN'T. ONCE.



NationsBank

SUPPORT THE 1996 ATLANTA PARALYMPIC GAMES.

quite as well as I, until this woman. My whole body was flushed, I was so turned on. I never knew just how sexual feet could be until that night. Just from having one foot kissed I had become completely fluid. It was divine.
In retrospect I'm glad I appreciated my feet so much, now that I know I'll never have them back. That way I have no regrets about ever taking them for granted. Now when I'm in bed with someone I pay great attention to their feet. Once I start kissing them I can't stop. It's more than just sexual for me though, especially since I just had my legs amputated only four months ago, it's become really emotional. Once it made me cry it was so intense for me. Sometimes it makes me scared how much I want to touch other people's feet. Just to hold them in my hands is something so big I can't even describe it. To people that do have feet: take care of them. They are amazing, sensual, precious things. Never take them for granted.

Bi Seeking

1/97

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Nail Polish

Nail polish has been a constant throughout my life. I do go through phases where I don't where any at all, but eventually it always comes back to me. Especially since this train accident I have been going polish crazy, buying it in vast amounts for me and all my friends. Ruby red with glitter. Deep ocean blue. Silver. Black with glitter. Bright orange. Turquoise glitter. Pale frosting blue. Pearly white.

About once a week I change my nail color. That's usually because the paint starts to chip and gets splotchy, so I like to scrap it and start over. One of the main reasons I love nail polish so much is because I have a constant need for change. It used to be that when I got bored I'd change my hair. But my hair is so short now, that I don't have very many ways to change it, and I've tried them all anyways, so I get bored with my "look." New nail polish relieves the boredom. It keeps things fresh.

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SOME TIPS ON DOING YOUR NAILS

My personal opinion is that it doesn't matter what kind of nails you have. As long as you've got nails, PAINT 'EM!! Who cares if they're short and stubby? Nail polish is a beautiful thing that will liven up any hand. Keep that in mind.

As far as color goes, go fucking Slather on whatever strikes your fancy. But do keep in mind that the quality of the different brands of polish do vary widely. While Wet N' Wild and Gumballs, two fabulously cheap brands that carry glorious colors are widely available and easy to get, they do lack quality. To get decent color and prevent them from chipping on the first day you have to apply at least three layers.



7

This can be time consuming. But it is well worth it. Just make sure that you let each coat dry enough before applying the next one, otherwise your nails may clump and the paint will go on splotchy.

Also it is a good idea to get a hold of a bottle of clear nail polish. Plain. This stuff is great for a couple different reasons. First of all you can put it on your nails before you paint because it prevents them from turning yellow from paint stains. Second of all, it is great as a top coat when you're all done painting because it prevents chipping (which is a bitch). Third of all, it's perfect if you just want plain shiny nails. Wear it solo.



NAILS, NAILS, NAILS

To close I would like to say: Nail polish is glamourous. It comes in every color of the rainbow and looks good on everyone. Right now I am wearing purple rain polish on one hand and pale lavender on the other. As far as I'm concerned, I could go naked and wear nothing else as long as I've got a good color of nail lacquer. I just love the stuff.

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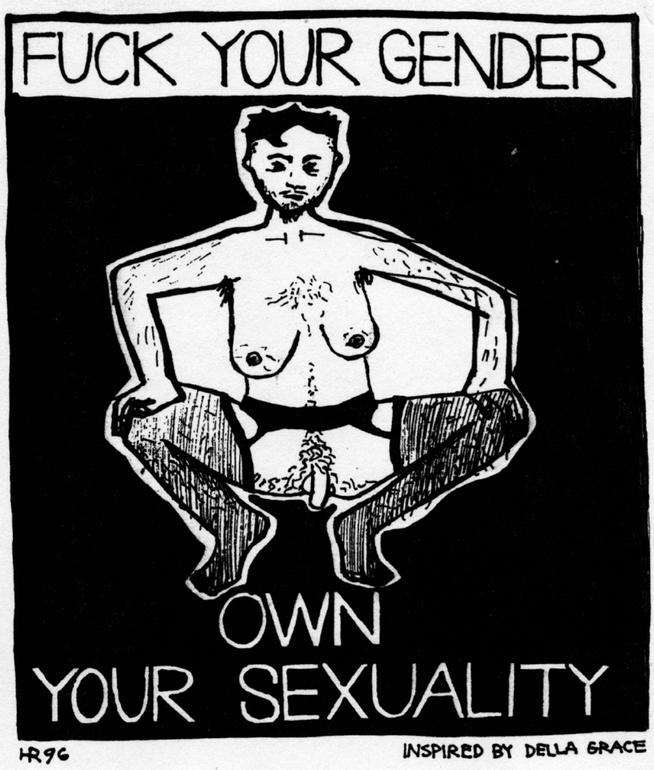

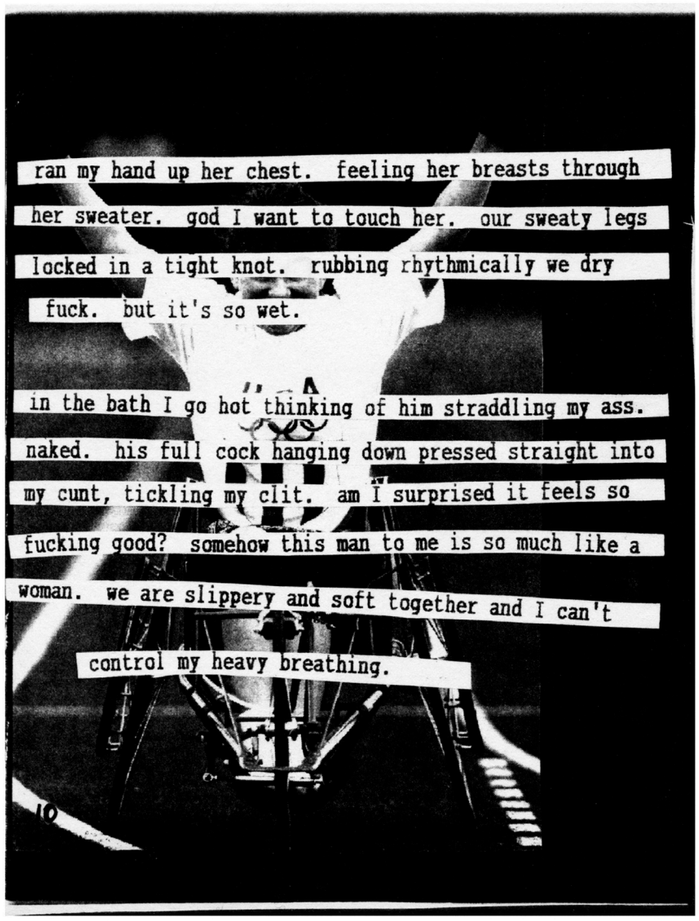

Dec 17.96.

sometimes all I can think when I'm stuck in my wheelchair is how I wish that someone would just come and take all my feelings of stupidity and sadness away, and fuck my brains out.

I don't care if I'm disabled.
I don't care if my legs are gone.
make me cum. kiss me.
let me touch you.
let me feel good with you and just fucking forget.

but other times i feel so fragile. like what i really need is a friend to hold me while I sleep, and not a bunch of bullshit passion.

XXX

and sometimes I get so mad I just want to beat everything down with an axe.

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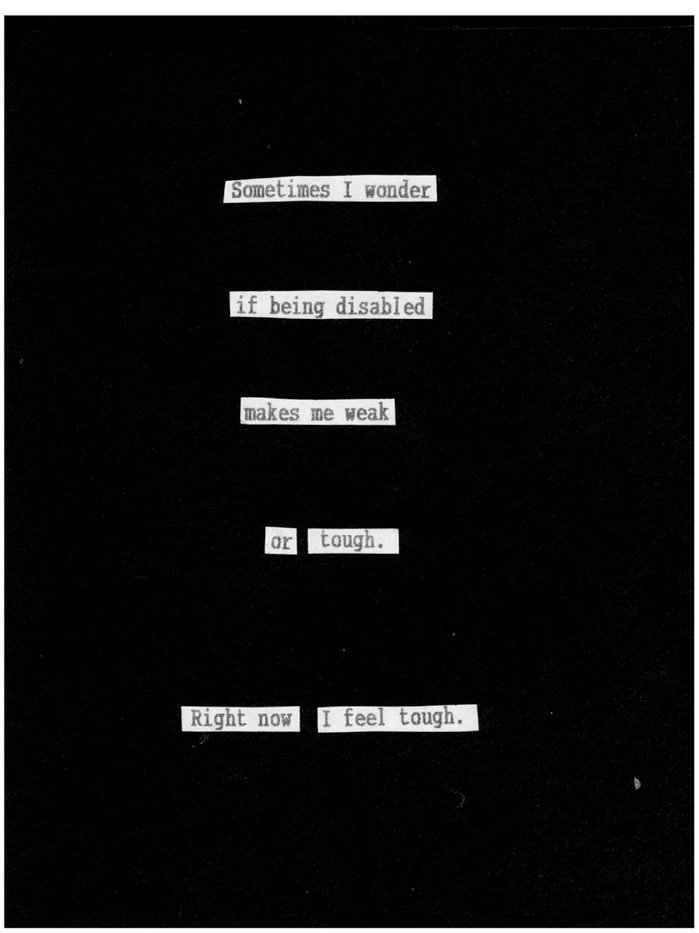


Nov 17.96.

I've been watching movies on t.v. about sick people. It's like I'm obsessed with anyone else that's ever been in the hospital.

I cry and cry and cry.

I alternate so much between being so eternally grateful for being alive and being okay, and sitting shocked in front of the mirror looking at my naked legs and thinking someone's played a practical joke and hidden my real body. I still wave my hands in front of my legs to make sure my feet are really gone. that it's not an optical illusion. I wish it was.

stupid. stupid. stupid. stupid. stupid. stupid.

that's how I feel so much of the time.

WALK THIS WAY

Learning how to walk again is a bitch. Maybe it doesn't sound that hard, but trust me, it is and I have it easy. Yah, both my lags were amputated below the knee, but that is my only physical limitation. Other people have paralysis, diabetes, burns, worse amputations, knee problems, old age. All these things can make something as simple as walking seem impossible. I never thought I'd have to learn how to do it twice.

Apparently babies learning to walk have a lot of pain putting weight on their legs for the first time. But eventually they get used to it and it doesn't hurt anymore. They say that will happen to me someday: that I'll be able to walk without pain.

But for a while it

SIR! MAY I SERVE YOU? SIR!
BiWM, 32, 6'1", 205lbs., seeks strict demanding yet affectionate master for LTR. Enjoy crossdressing nudism B&D, CBT, enemas, and pleasing my master. Age, race open. ♀ 3134

hurt so bad that I just couldn't believe that. Now, finally, my pain is starting to go away and I actually like to walk. This, I think, is a miracle.

When they teach an amputee how to walk again they start them out on parallel bars. Next a walker. Then crutches, then one crutch, then a cane, then nothing. Right now it has been four-and-a-half months since my amputations and I am on crutches. In a month I should be able to start walking with a cane, at least for short distances.

Today I walked outside on the street for the first time since I lost my legs. I just walked from house to truck, truck to diner, diner to truck, and back home again, but it was exciting. To take steps on wet, uneven concrete was a big deal.

It's funny because I waited a long time for this "big day" to walk outside. For some reason I thought that if I was finally on crutches, and my pain wasn't so bad, and I could throw a pair of jeans on over my new robotic legs that it would all be like it was

before. Like if I got to this certain point it'd be like I was "normal" again.

Well, I looked in the mirror and I'm not. My walk is funny. My knees are bulky from the thick elastic sleeves I have to wear to keep my legs from sliding off. It's obvious something's different. But for some reason, in my head I guess I thought that if I worked hard enough that being an amputee wouldn't make me different. Or at least not noticable. I guess I hoped it was something I could hide better. I just want to be the way I was before the accident. I don't mind having fake legs, as long as I can walk with them as gracefully as I did my old legs.

OBSTACLES

You wouldn't think things like stairs, rugs, dark rooms, gravel, grass and curbs were all so difficult would you? But they are. When I have to practice stairs in physical therapy my heart starts beating real fast and I get totally scared of losing my balance and

TOUGH ASS BITCH
don't take no shit. Dress in drag as a way of life: butch or femme. Spanking, kisses awarded to ladies who can talk about the heavy shit such as F-on-F domestic violence. Outlaws only need apply. ♀ 5239

falling over. It's hard to step down when all your weight is on the leg that's supposed to bend, especially when you don't have a flexible ankle. I'm so afraid of falling. When that happens I just focus, breathe, and try to relax. I tell myself I can totally do it, and calm down.

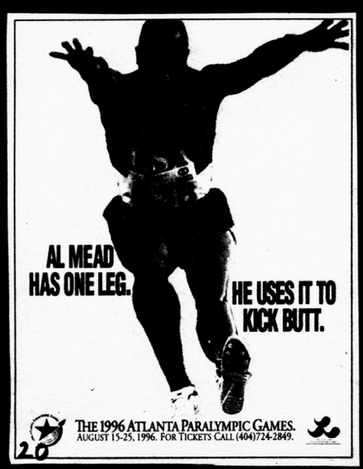
PSYCHING MYSELF UP

One day my legs were really tender, and I was practicing standing at home with my mom. But every time I would stand up I would fall right back down because the pain was so horrible. I got mad at myself cuz I thought I was being a wuss and I just needed to be strong and work through the pain. So I kept going. But every time I stood up the pain was so intense that I burst into tears and I was getting so pissed at myself. So every time before I would stand I would close my eyes and focus to make myself stronger. So would my mom. She said she visualized white light and angels carrying me so I had no pain. But I envisioned something much different.

I thought my pain was my fault (which it

wasn't) and it made me feel weak. So I needed to visualize something strong to be able to stand and face the pain. I took my sadness and focused it into anger. In my head I saw myself with my fake legs on strutting around like a tough ass bitch. I was wearing a slutty black dress, a leather jacket and lots of eyeliner. I had a martini in one hand, and in the other was a knife that I held to the throats of all the men and women who design non-wheelchair accessible bathrooms and buildings. I was in control

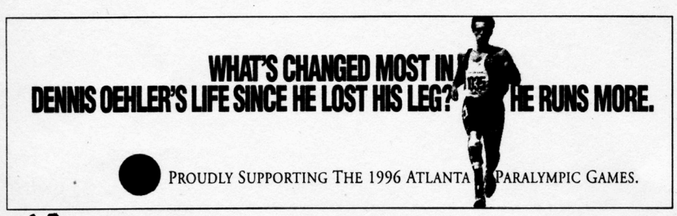
and I was walking perfectly.





DISABLED SLUT

Having sex as a disabled person is different than it was before I was disabled. I have to maneuver myself around differently. Because both my legs were amputated it makes it harder to be smoothe in bed. I have to always prop myself up on my knees cuz I have no feet. I would wear my prostheses (fake legs) in bed, but they're not so comfortable, plus the ankles on them don't bend, so my feet are always sticking up funny at a 90° angle. In other words I have to plan out every move I make which takes out some of the spontaneity of sex, and makes me embaressed sometimes too. Sometimes I get self-conscious. Thats another reason why having sex as a crip can be different, I'm more vulnerable. I



remember laying in the hospital bed after the amputations were done wondering if people find me sexually attractive anymore because I was now "crippled". Let's face it, on the whole most handicapped people are basically ignored by society. This means we are not getting checked out as date material. I guess I was worried I would be ignored. Lucky for me though, both the people I have been dating since the train accident have been incredibly supportive. When we're together they kiss and touch my legs as if they are beautiful things. They are gentle to me, but at the same time they treat me normally, not like I were made of glass.

1/97



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STUFF I RECOMMEND

"DOC AND FLUFF" a novel by Pat Califia. So fucking awesome. Lots of hot queer sex, and a great story.

"TRANSGENDER WARRIORS" by Leslie Feinberg (my personal hero) his personal trans history + a history of the trans community.

"TEEN FAG" zine issue #5 the medical issue. great interview with an amputee and other wierd & medical stuff.

"DROP DEAD": zine of lesbian butt-ering" so fucking awesome. My favorite zine of all time. personal accounts by a survivor of dyke domestic violence. P.O. Box 28733 SEATTLE, WA 98118

"WHAT HAPPENED TO YOU?" anthology of writings by disabled women. EDITED by LOIS KEITH. all sorts of writings by different women w/ different disabilities: paralysis, blindness, everything. I didn't relate to it all, but it's still good.

"ANONYMOUS BOY" punk fag sex comics. classic + sooo good. "It was at our third rehearsal that I fell in love with the way Ernie's nipples got all pointy when he played." WRITE: c/o Tony Arena 321 west 16th st. #2W New York, NY 10011

"BODY ALCHEMY" by Loren Cameron. photography and writings on life as a female-to-male transsexual. Gorgeous pictures.

"WHOA, NELLIE!" by Jaime Hernandez from Love + Rockets. put out by Fantagraphics. BRILLIANT Girl-wrestling comic. 3 ISSUES.

PUNK HOMOS!!

24

you don't call
and don't call
and don't call

and I say
fuck you

but in the bathtub
I end up
masturbating
to a fantasy
about you
anyways.

stupid. stupid. stupid.

AFTER YOU FLOGGED ME
both our backs itched. Was it Dracula we saw? Did you think I was a mouthy, neurotic over potty-trained snot? It's been a long time since way back when. I'll pay you back. Try me again. ♀ 2798

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LIST OF IT SUCKS TO BE

★ pain

★ in my wheelchair, in public, I become invisible

★ either that or I'm stared at like a freak "where are her legs?!"

★ It'll be months before I can leave the house by myself

★ I went to stupid fucking Barnes + Noble and they didn't have one fucking book about disabled anything

★ sometimes I try to talk about it to non-amputees and they have nothing to say cuz they don't get it

★ hills and stairs

REASONS WHY AN AMPUTEE:

★ people stop calling me cuz they can't deal FUCK 'EM ANYWAYS

★ there's a lot of dances I'll never be able to do cuz my fake ankles and feet barely bend (I love ♥ to dance)

★ being jealous of people with feet (or a foot)

★ non-wheelchair accessible parking, vehicles, buildings, bathrooms, dressing rooms, seating, doorways, concerts

★ feeling like a burden cuz I need help with so many things

★ feeling like a drag to hang out with cuz I don't have the freedom to run around town like I used to

LIST OF IT'S BETTER TO

★ I always have plenty of leg room

★ I can stretch out comfortably on the couch

★ I don't have to worry about corns or warts

★ I'll never have cold feet wet feet fallen arches

★ I can ride the bus for 25¢

★ I get to use handicapped parking spaces and I never have to pay a parking meter again

★ I fit into the bathtub just perfect

★ I can wear peglegs

★ removable body parts are always cool

★ I'll never have arthritis in my feet or ankles

★ I can forget about clipping my toenails

REASONS WHY BE AN AMPUTEE

★ I've got cool scars to show off at parties

★ my new legs can make me however tall I want to be

★ I get $ from the government, food stamps, free school and my medical bills covered because I'm "disabled"

★ my feet never stink

★ I don't have to change my socks

★ all the nickname possibilities

★ while the rest of my body gets older, my legs will remain forever young and high-tech

★ I'm even more of a tough ass bitch than I was before

★ modern prosthetics (fake limbs) are fucking amazing

SHOWER MASSAGE VS. THE TAP

the age-old debate

When masturbating in the bathtub there are two basic methods which you can use: a shower massage shower head, or the classic all-American bathtub tap. Personally, I am a serious fan of both, but I am here to present the pros and cons of each, so that you can judge for yourself.

First let's talk about shower massage. Shower massage is good for a really quick orgasm. IT'S BENEFITS ARE it's easily adjustable power settings and it's easy maneuver-



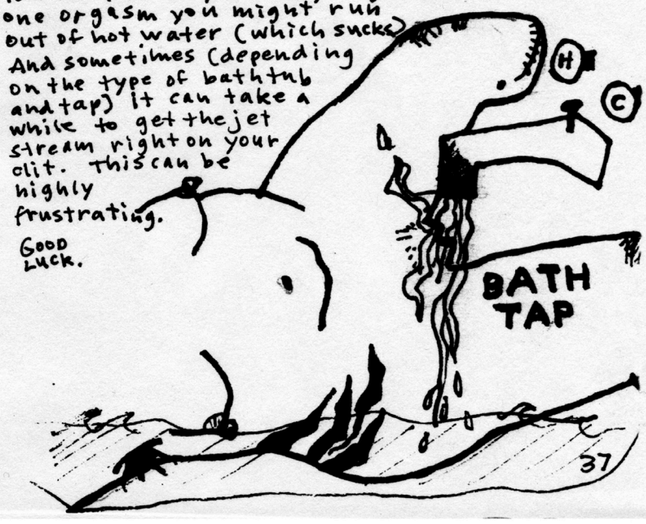
ability. you control which angle you want to hold it at, where you want it to aim. It's all up to you. The first time I tried it I came so fast I nearly got whiplash. Fabulous for a good quick fuck.

HOWEVER, the general consensus between me and some of my friends is that the shower massage is so powerful that after you cum once, it leaves you kind of desensitized, and it's really hard to cum again.

Now, the bath tap is great because of it's sensuality. You can lay there underwater with the jet stream hitting your cunt and your hands are left free to play with yr nipples. Also, the bathstream feels much better on yr cunt and asshole than the shower massage does. Also, with the bath tap you can cum over and over, each one building off the last.

THE DRAWBACKS ARE it usually takes longer to cum this way, so if you go for more than one orgasm you might run out of hot water (which sucks) And sometimes (depending on the type of bathtub and tap) it can take a while to get the jet stream right on your clit. This can be highly frustrating.

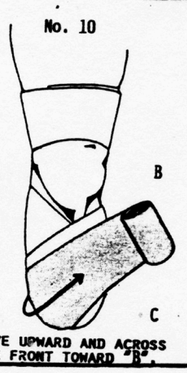
Good Luck.



CRIP LOVE

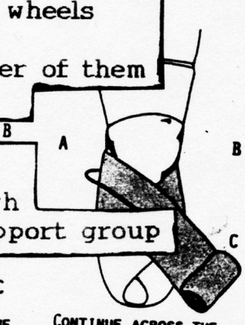
amputee girl
you make me wet
I wanna lay with you and
bite your bitten lip

spread lubricant all over
the stumps of your legs
and cum



when I see you wheeling yourself down the
hallways of the hospital
I look at your hands on the wheels
and I imagine
sucking each and every finger of them
like they were our feet

amputee girl
you are mother fucking tough
you come to the amputee support group
looking like Lili Taylor
and you talk the shit



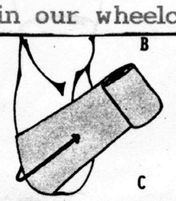
IT FUCKING HURTS
IT FUCKING HURTS TO BE AN AMPUTEE

you say it so perfect

I speed up my wheels and push myself real
hard passing people along the way so I can
casually sidle up to you
both of us at eye level in our wheelchairs

"Nice hospital robe.
You get out tuesday?
That's great.
Good luck.

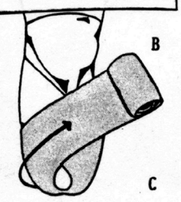
You're so fucking brave."



beautiful amputee woman
I look at the casts on your legs
and then into your eyes
and I see you look at my fake legs
and then my face

and you totally know

without saying it
you know how it feels



I jumped off the train and next thing I knew, I'd fallen close to the tracks but I didn't know how close till I looked down at my legs and I couldn't get up off the rocks cuz they were torn to shreds.

Oh my god, I thought.
Oh my god. This is my life.

I just got run over by a fucking train.

It hurt but my body was in such shock that it actually wasn't too bad.
What I remember most is my heart pounding more fast than it ever had and my body was so hot.

Burning hot, terrible heat.

I screamed for Lemur and told him to call 911. I was in surgery for seven hours. When I woke up I didn't know what had happened cuz I couldn't feel anything. I finally asked Lemur and he said they'd cut off both legs below the knee. I didn't want to look.

40

Dec 22.96.
Every day I have to practice standing and walking and every day it hurts. There is not one day that goes by I am not in pain. It is hard to motivate myself to walk because it hurts so much.

I am always hurting. always hurting.
always. always. always. pain. pain. pain.

I'VE GOT THE TICKETS 4 U
You be the date. ISO cute dyke to join me for Melissa concert Dec. 13th. I am cute, femme, HWP, 20's. You be: single, 20-30, HWP, attractive butch or femme. Meet 1st, then Melissa? ♀ 2797





So, are you gonna go for it? or are your hands going to stop mid-thigh? come on, I dare ya. I dare ya to torch it. Come on, touch the ends. The stumps. What are ya, a fraidy cat?

Fuck you if you are.

ASSASSIN BITCHES IN HEAT

As the army tanks were coming, so was I. Me and my girlfriend had just bombed the White House and we were celebrating... she had me draped over the back of a chair with my wrists tied to my ankles. My skirt was up around my waist and my tits were popping out of my purple push-up bra. I just love purple. It's a good thing too, cuz that's the color my arms are gonna be tomorrow, and my ass, and my thighs. SHIT she beat me hard. It felt so fucking good.

... I'd driven us back from D.C. with Glory (that's her name) in the back seat armed with a whole mess of guns most of which I never even heard of before. our terrorist collective back home had supplied us with them, but me and Glory had accomplished this mission alone on account of it's monumental risk factor, and the truth is Me and Glory are hot shit. we'd bombed plenty of morally-decrepit places before, seemed like the White House was just an explosion waiting to happen.

We were riding high on a wave of adrenalin and my baby had me excruciatingly tensed, hunched over, waiting. "FUCK ME ALREADY, YOU BITCH!!!", I yelled, trying to piss her off so she'd start whipping me, but she started with something else: clothespins. She began at the top of each arm, pinning me every inch or so, till they were sticking from my skin like a picket fence. Then she took some more and did the same thing to my legs, starting near my knees and working up towards the smoothe (I shave) lips of my cunt. Each pinch made my skin



more hot than the last, and the pain was subsiding as my skin went numb. she took four more clothespins and clipped two each onto the increasingly flushed (and very impatient) lips of my labia. yum!!! she went away for a minute and returned with a bottle of lube and a black toolbox which I could tell was full and would contain some things that

would be of particular interest that evening. Next thing I knew she was shoving a very slippery butt plug up my ass. It wasn't very big, but it felt good and my asshole relaxed as it went in. mmmmm...

I stood there feeling good and wanting more when Glory pulled out her riding crop and started smacking it against my ass in twos. One quick hit after another made it sting longer. As she started hitting me harder and faster (Glory's got big beautiful arms) she turned on the t.v.. The nation was in pandemonium from the White House shock and every channel was covering the story in a special news bulletin: "The bombing appears to be the act of some sort of militant homosexual disabled person's terrorist group. Just outside the bombing wreckage was a message in red spraypaint which read "QUEER CRIPS SHALL PREVAIL UPON THE DEATH OF SOCIETY." No one knows exactly who is responsible but an investigation is underway. The death of the nation's leaders and cabinet is a serious blow to the people of the United States. The army has been called in..."

Glory kept beating my ass as she laughed hysterically. "Yah, a fucking lot of good the army'll do. The president's already dead,

it's not like they can fucking bring him back." The neon glow from the t.v. reflected on her face as she bitched about the government. And with that crop in her hand she looked like one scary ass bitch. MY DREAMGIRL!!! She hit me and hit me till my ass was grass and I cried purple rain.

I stood there, still draped over that chair, with blood rushing to my hanging head as I panted and panted for air. "I love you honey," Glory said, as she stuck her upside-down head down next to mine and kissed me full on the lips. cherry lip-gloss. delicious.

Immediately she stood up and in one swift move she pulled off all the clothespins and I screamed. FUCK, THAT HURT!!!! The feeling in my limbs was starting to come back and it was painful. kind of like frostbite. "That was the warm up," she said. My body was so hot I could start to imagine what the White House felt like. Nothing but of acres of fire and smoke.



she took both her hands and scraped her nails (which were filed to a long black point) up and down the most tender parts of my body, digging hard. As she clawed her way down the sides of my waist, and my bruised thighs, arms and ass, she drew ten thin streams of blood which dripped slowly into a stain on the floor. "You'll clean that up later," she said.

My eyes were half shut and my jaw was locked from pain but when I thought about what was yet to come my cunt would throb. As I tightened and un-tightened my asshole around the butt-plug I wondered how much fatter my pussy lips could possibly get. I was so ready.

Glory's whip slithered out of her metal tool box like a snake, uncoiling itself as it hung to the ground from her firm hand. It stretched six feet long and was fashioned from small braided wires. Glory had made it herself, and she used it like an artist. Her control over the whip was precise. She could make it land exactly where she wanted it to.

I stood, swollen and scratched, holding my breath. My mind was blank except for Glory and her wire whip. Everything was silent and then the air cracked: SMACK!!!!! I knew the whip had hit me but my body didn't feel it for a few seconds and then GODDAMN, she whipped I winced. The pain was intense.



me again. CRACK. Each stroke sliced my back open like a scalpel. She made me count them out loud and thank her for each one. SMACK!! Three, thank you. Four, thank you. Five, thank you. My mind left my body, but I'd asked for this, I wanted this. With my baby it was okay. Through clenched teeth, I said "ten, thank you." And it was over. She laid the whip down. Neither of us said anything and for a few minutes all you could hear were the sounds outside of the country racing around trying to piece itself back together.

I was lost in some sort of spiritual state, almost like a prayer, when the snap of Glory pulling on some latex gloves brought me to. DESSERT!! She paused to grab some more lube, and kicked my knees apart. SLICK. she spread her slippery fingers through the fat lips of my cunt. The latex felt cool against my steamy skin and I pushed my ass as hard as I could against her hand. Slowly with her middle finger she traced a few circles around my clit then suddenly withdrew her hand and slipped three fingers

into my cunt. FUCK, that felt so good. she moved them in and out, slow at first, and as I panted more she started fucking me faster. My vaginal walls were teasing and relaxing against her fingers. Her latex gloves no longer felt so cool. She withdrew her hand and reentered with four fingers, and then five. My cunt was slippery as a motherFucker. They slid right in. My cunt walls clenched at them wildly as she shoved in and out.

MORE YOU BITCH MORE!!

"Fuck you then!!" she screamed and next I knew she was fisting me, her whole hand just barely squeezing inside me, moving slow. DAMN. I felt so tight I couldn't even move my legs (even if they weren't tied down.)

My breath was running quick and my body felt like one big itch that needed to be scratched. Her left hand still inside me, Glory pulled her butt-plug outta my asshole and and started playing it with her right hand. Before I knew it she was fisting me there too.

Glory had me exactly where she wanted me: exhausted, beaten, bloody and wound-up like crazy. I thought I would burst. I still hadn't cum

yet. "JESUS CHRIST," I yelled. "HOW MUCH MORE CAN A GIRL TAKE?" And with that she withdrew both fists, untied my ankles from my wrists, pulled me off of the [redacted] chair and threw me on the floor. "THIS BETTER BE GOOD" I thought. And before I knew it I was on my back with my legs kicked up over her shoulders and she'd shoved a glyde dam over my pussy. Her tongue barely even touched my clit and all the tension from our mission, the drive back from DC., her whipping me, and the double fisting merged to this humongous point till I knew there was nothing to stop it and my body jumped. I came and came and came with my legs kicked wide and my ass in the air. I came so hard and so long my bod wouldn't stop shaking for at least a half hour, and every limb in my body tingled.



Glory kissed me and kissed me. Soft kisses all over my back and arms as I just sat there, all curled up, feeling wonderful. Then she laid me down, covering me with a blanket and rolled under the covers with me, curling

herself around my body and rocking me to sleep.

The next morning we woke up and ate nails for breakfast. We had work to do. "Baby," I said, "seeing as how we just bombed the White House, [redacted] killing the President and the Cabinet, I don't see how it would be a bad idea for us to leave the country."

AND OFF WE WENT...

LOOK FOR
VS IN
YOUR
TOWN!!!
...

XXX VAMPS ROCK XXX

TRAINS...

Ever notice how many fucking movies have trains in them? How many songs are about trains? How many towns have train tracks in them? For the three hours before I jumped off the train and got hurt I loved trainhopping. I still think it's great, but I'll never do it again. I'm not down on trainhopping, but DON'T DO IT UNLESS you totally know what you're doing. DON'T jump on or off if you don't feel safe. DON'T do it if you're tired or sick or out of it. trust your instincts.

NIPPLE JEWELRY *

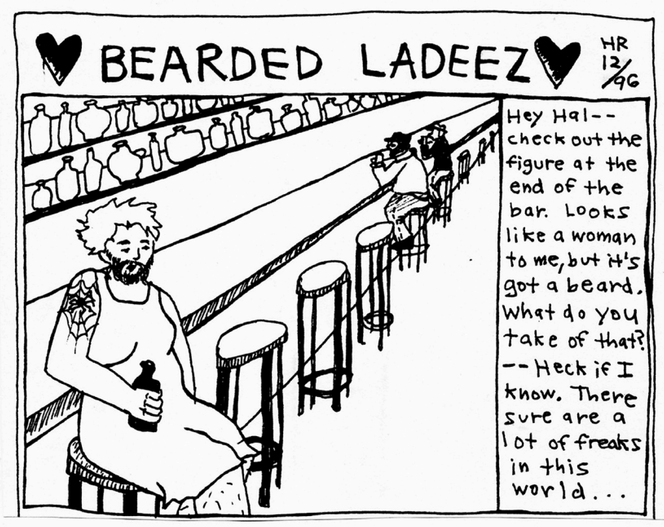


NIPPLE PIERCINGS

last week I was smooching my girl friend. laying on top of her, kissing her stomach, sprawled in my bed. when something happened to me that never happened before: my nipple jewelry got caught in her fishnet stockings. I laughed and carefully untangled myself from her thighs. it happened a couple more times before I finally pulled them off. fishnets are more dangerous than I thought.

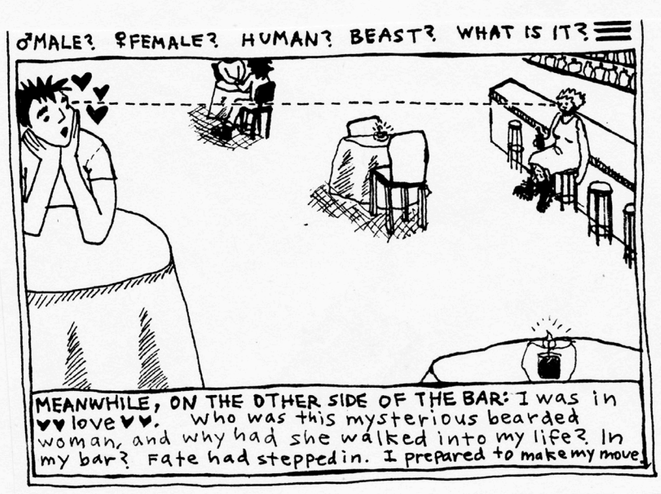
I AM SO FUCKING FEMME
I can't even deal w/ myself. You are butch, easily agitated, ashamed of your poetry. Must have no sense of style. Chain-smoking a+. Must be willing to watch me dance to Sinatra. ♀ 9942

67



BEARDED WOMEN
It wasn't until this summer that I began to realize their true erotic potential. Women with facial hair are fucking hot. The truth is that a whole lot of women do have facial hair but they shave it, so you'd never know. But a woman that lets hers grow, to me, is making a strong sexual statement. It's total gender fuck.

68



WE ARE THE DOPEST GIRLS
in the world. We want girlfriends. No ravers, no butch hussies, no boring lesbians, 18-21yo, any race, no prudes. Vanilla sex OK. ♀ 8942

69

TRAUMA

I've never had problems with hospitals or dentists or needles or blood, before, or since the accident. But I'm nineteen and I've been in surgery twice now, and **both** times were emergency situations that I wasn't prepared for. Both involved my legs. It's scary.

I felt like one of those characters on M·A·S·H: the soldier patient who wakes up from surgery and says "where are my legs?" I woke up from a seven hour surgery in a bed in the intensive-care unit. I was so full of drugs I couldn't hold my own head up. So full of drugs that all I did for the first few hours was throw-up because my body couldn't take it, and so full of drugs that I couldn't shit for 10 days. (heavy drugs constipate you.)

Drugs are something I could talk about a lot. I was on painkillers for about four months after the accident because I couldn't sleep without them. Directly after the accident, painkillers were the

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one thing I felt like I had control over in the hospital. I had my own morphine drip attached to a tube in my arm. Whenever I felt pain I could just push a button next to my bed and I'd get drugs. I controlled it. I did not, however, control the catheter they gave me. I had this tube in my bladder that was supposed to drain on it's own, but it wasn't draining and I had to pee really bad. It was just backing up inside me and not going anywhere. I told my nurse and she told me it was all in my head and that if I wanted to pee I could. Well, I tried and tried, and finally I did pee. All over my fucking bed I peed. The fucking catheter was in wrong the whole time.

Other highlights of my hospital stay at HIGHLAND HOSPITAL IN OAKLAND, CA were:

Laying on a stretcher with my legs crushed, calmly asking if they would knock me out. It wasn't until I signed the papers saying that yes, I

Hilary Taylor Russian DID understand that both legs would probably be amputated in an immediate surgery, and Did I give consent?, that they gave me the drugs.

My robotic doctor waking me up out of a dead sleep six days after my big surgery to wrap my legs in plaster casts, even though it had been several hours since I'd had any pain medication (not that he asked.) And when I said "But... I haven't had any morphine in four hours..." no one listened. And I tried not to cry. I tried to take it, to leave my body. I thought of my sister at home playing the piano. I thought of my best friend's freckles. I thought of flying through the sky all alone. But it was the worst pain I ever felt in my whole life. Worse, even, than the accident itself, because then I was numb. But now I felt it all. I couldn't stop screaming and crying, crying. And they wouldn't stop. I had no control. The fucking doctors wouldn't stop. Finally a nurse heard me screaming from the across the hospital, and came running to give

me a pain shot. (bless her)

HALLOWEEN

surgery #2 was supposed to be a routine check-up with my doctor two months after the amputations were done. But they discovered an infection in the suture line of my right leg and wheeled me off to surgery. It was so crazy demoralizing. I was having a shitty day already dealing with being a new amputee and all of a sudden I'm faced with another emergency surgery. When they came to wheel me off to the ER my Uncle was in the cafeteria and I was all alone. All alone. I was so fucking scared all I could do was rub my tiger's eye agate (From Tracy for strength) back and forth in my hand for courage. They re-opened the suture line of my right leg, cleaned out the area and sewed it back up.

TRAUMA

Trauma can be anything. It can be a fire. A death in the family. A bad car accident. Cancer. Rape. It can be anything at all. But what it does, is it comes along and changes your life in

a split-second. It's effects come in many different phases and they are long-term.

One minute I had feet + calves. The next minute I didn't. First I have to accept this. Then I have to start to accept my new body. Then I have to accept that I'm in a wheelchair. That I'm disabled. That I can't do a lot of things for myself. That I have to move back into my parent's house and sleep on their couch for five months because my wheelchair won't fit through any of the bedroom doors. That I have to get plastic legs. That I have to learn how to walk all over again. That I have to learn to live with daily pain. That I have to go to the hospital three times a week. That I have to figure out a way to pay for this. That I get stared at every time I go out in public. That I constantly have to explain to people how I lost my legs. That as everyone else's lives are moving forward I still can't leave the house by myself and I have to be patient. That no matter how proud I am to be part of the disabled community, and how determined I am not to let this accident ruin my life, I will never get my legs back.

SEXXXY

2.97

It's really important for me to feel like becoming an amputee hasn't ruined my life. That includes my sex life. It seems like ever since the train accident, I've been determined to become the sexxiest amputee ever. Like, ~~■~~ If I'm just totally totally hot it won't matter I'm disabled cuz you'll be slobbering so much you won't notice. OR even better, you WILL notice and it'll make you want me more. Well, for the last five months I've had to wear these ugly, tan, thigh-high sock things 24 hours a day (except for bathing) because

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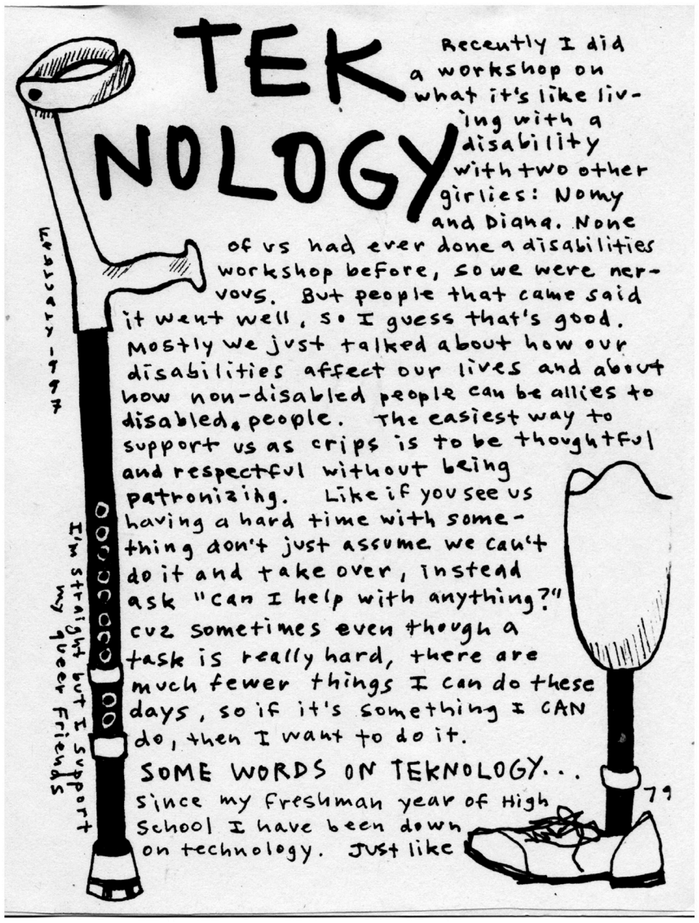
I ♥ AMPUTEES

they're tight, and they keep the circulation in my legs going so they don't get swollen. Well, they're butt ugly and I hate them. Whenever I sleep with anyone I ~~■~~ ~~■~~ can never get totally naked cuz they always have to stay on. It's so NOT sexy. Ugly tan nylons. Blecchhh. Needless to say they've been giving me grief and bad self esteem. So, this week, when I finally figured out a way to eroticize them I was way excited. I liberated myself a red + black vinyl bustier with a bunch of garter-belt, and realized that my ugly tan socks are just the thing to hook onto my garters. Yay !!!! I've felt soooo much better ever since I figured that one out. I hated feeling like being an amputee holds me back, and that was how those ugly tan socks made me feel. Now all I have to do is figure out how to dye them black.

★SPECIAL THANKS★

...to devon for making me a matching homemade flogger out of bicycle tubing. Amputee Dominatrix

77



CARS, PAVEMENT, PLASTICS!!! oh my!!!

every other eco-friendly kid I know. But now I'm disabled and I can't leave the fucking house without other people's help, and my wealthy godmother has offered to buy me a car with hand-controls. Before the accident I would have said hell NO!! I thought cars were unnatural, bad for the environment, too expensive, and unnecessary. I thought concrete was gross. America's obsession with gasoline was causing war, and it was all fucked. WELL, WHAT-EVER. Cuz now my legs are amputated, I'm stuck at my parent's house and I'm going crazy, and if I had a car I could take myself to the grocery store, the movies, to other towns. I could have personal freedom and Sanity. So I'm gonna take that car, and if other people don't understand, well fuck 'em. I still hate concrete, but if the streets + sidewalks are going to be paved, don't you think they should be done so smoothly with curb cuts so perple on bikes and in wheelchairs can use them?

80

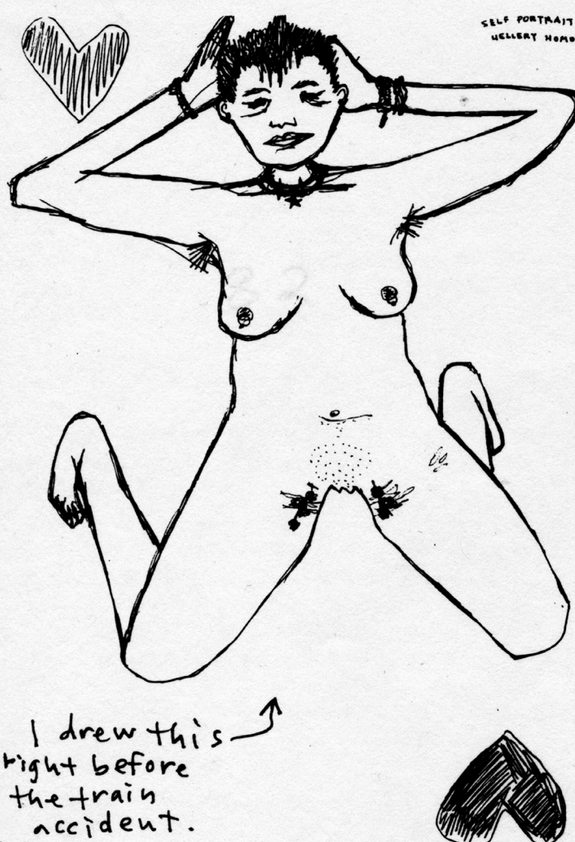
I ♥ NATURE

Nomy said something at the workshop that I've been thinking about a lot. she was talking about how because she has a fake leg she can't really connect with nature like she wants to. she can't just take a ten-mile hike through the woods, or just run into the ocean (she has to stop and take her leg off first.) And how no matter how far away from the city and civilization she gets she is still attached to her plastic, robotic leg.

It's scary to think that six months ago I was all down on technology and now, because of my disability I'm all dependant on it. Crutches, prosthetic legs, wheelchair, car, paved walkways. I still have a lot of guilt about the car thing. But I appreciate it. I appreciate it so much. I keep thinking what my life would've been like 100 years ago if this happened, and it would've been radically different, I think. I feel so lucky to have fake legs, and crutches and a car. I'm still not PRO-TEKNOLOGY or anything, but I APPRECIATE the difference it makes in my life.

I ♥ SWIMMING

81



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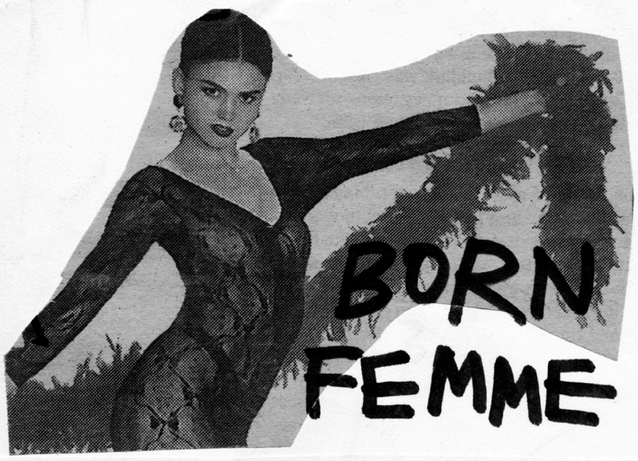


The prominent dress style for dykes here in Seattle is the tomboy look: hiking boots, flannel shirt, jeans and a baseball cap. When I came out as a dyke at 16 I knew that I didn't have to start dressing like a tomboy to be a "real" dyke, but I did so anyways because I thought I wouldn't get dates with girls otherwise. Who was I fucking kidding? For a year-and-a-half I cast aside dresses and lipstick and attepted to butch out. It was so sad. I made a terrible butch, and consequently I didn't get all that many dates either. It just wasn't me. But I was having problems at work: I kept getting hit on by 83

man after man, and passed up by every hot girl that walked through the door. What was I doing wrong? I thought: Isn't it fucking obvious that I'm a dyke? What do I have to do? carve the word into my forehead? Shit! So, to solve the problem I had Eve give me a crew cut.

Well, something magical happened. Even though the haircut was horrible on me (how many dykes do you see on Broadway with bad bleached crew cuts?), I all of a sudden felt *so butch* that I figured I could start to fuck around a bit with my wardrobe, and I started wearing short skirts and fishnets again. Hallelujah! I felt reborn. I totally femmed out: lipstick, everything. Me and Eve would step out together, me looking like a dyke tart, Eve: my butch mama, and people started asking us if we were a couple. It was fabulous.

That was about a year ago. Since then I have learned not to kid myself. I am a slutty dyke femme and proud of it. I think it's dumb that I thought I couldn't be a femme and a dyke at the same time. Well now I know better. Femming out is where it's at. I couldn't be a happier girl!!! LIPSTICK LESBIANS RULE
84

FUCK YOU

I DON'T NEED YOU.



85

FREAK OUT

SOMETIMES I FREAK SO MUCH THEY STOP BEING FREAK OUTS AND JUST BECOME MY DAILY LIFE. THIS IS STUFF I WROTE AND THOUGHT MILLIONS OF TIMES OVER THE PAST COUPLE MONTHS...

I don't know about how you're supposed to deal with trauma. So, whatever. I do what I can. After five months of sleeping on my parent's couch in the suburbs I tried moving back to Seattle. Everything fell apart. My house was on the brink of eviction, so everyone was packing to move out, and I wasn't really walking yet, so now I'm back at my parent's house. FUCK.

I realized this week that I haven't been out alone in public in five months (now seven months). I'm scared to be alone. I get so fucking vulnerable: afraid I'm gonna run into some acquaintance who will wonder why I've got on plastic legs. Fuck that. I'd leave town if I could, but I can't walk very far. TRAPPED.

86

INFANT, INFANT,
I FEEL LIKE AN INFANT.

Devon was pushing me in my wheelchair as I was sipping on a lemonade, and I was freaking out. I felt like a fucking baby being pushed in a stroller, sucking on a bottle. I started thinking how everything in my life is baby-ish because of the accident. I can't walk, I crawl around on my hands and knees, I've been too depressed to feed myself so I need other people to help me. I can't leave the house alone. I rely on my family and friends to protect me from almost everything. I felt like I was being potty-trained for three months after the accident because my wheelchair wouldn't fit into my parent's bathroom. I had to use a portable toilet with a bucket that my mom would empty for me every night.

NOW, SEVEN MONTHS AFTER "THE TRAUMATIC ACCIDENT" I still haven't gone out in public alone. I'M SO SCARED. what is my problem? What? Before the accident I was so fucking independent. I was free. I ate alone, saw movies alone, went to art exhibits alone. For fun. Now

I feel like this major drag to my friends because my first instinct now is to tag along with them. I can't stand to be left behind. By myself, I'm scared. What if I needed help with something and I was all alone? What I need help with now could be anything: help carrying something, reaching something, help getting the door, answering the phone, help by keeping me company and distracting me from things I don't want to think about. BUT I'M WALKING NOW. what's my fucking excuse? I can finally catch a bus somewhere all by myself. BUT I'M FUCKING SCARED SCARED SCARED.

I went from having a totally busy, independant life to seven months of hibernation. I dropped off the face of the Earth and slept on my parent's couch day after day after day. I did a lot of crossword puzzles. I spent a lot of time at home alone, accepting the fact that I couldn't go out and that I was suddenly limited in a bunch of ways that most other people weren't.

"AND, NOW ALL-OF-A-SUDDEN I'M SUPPOSED TO PICK UP WHERE

I LEFT OFF. Goddamnit it's hard. okay, I know it doesn't sound hard. Just walk up the hill and catch the bus to pike place to get some blackberry cobbler. Go to the movie theatre, open all your own doors, carry your own backpack and sit down by yourself just like you used to... The idea is what I want, but the reality is scary.

RED, BROWN, BLONDE OR BLACK 89
I worship women's pubic hair. SWM would love to bury his face in your beautiful, hairy pussy. Hump my face and make both of us smile. ♀ 3141

Mar 1997

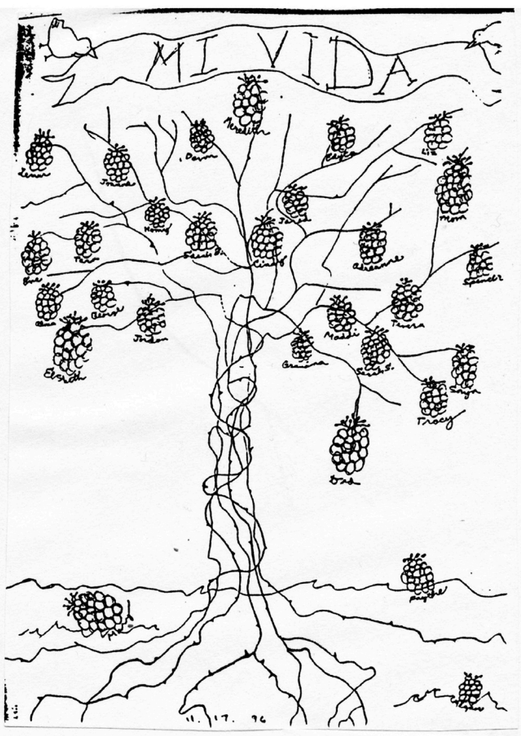
PIGEON-TOED

I have always been pigeon-toed. My whole life, ever since I can remember I walked with my feet pointed in. When I was five my mom took me to the doctor to correct it but there was nothing we could do, that's just the way I walk. When they amputated my legs, one of my first thoughts after surgery was "Oh no, I'll never walk that way again!" I loved being pigeon-toed, and I got all sad thinking that part of my life was over. It was my trademark walk. I read in a book somewhere that pisces stand with their feet pointed in, crossing each other because it imitates fish... Well, a great thing happened to me in physical therapy this week. Without even thinking about it I was walking pigeon-toed. I freaked out, I was so happy. It turns out that my walk is all in the way my knees rotate my feet in. Even though I don't have my feet anymore I still have my knees, so I still have my walk back. It is so tremendously major I can barely deal.



ARE YOU A FEMALE JERRY LEE LEWIS?
Boogie-woogie pumping piano man, 37, seeks boogie-woogie pumping woman. Let's compare boogies, you take the bottom & I'll take the top & vice-versa. Tom ♀ 2854

90



THANK YOU LIST Loren Cameron, Chris
Thank youz for constant inspiration go to Charlotte Cooper, Anonymous Boy, Frida Kahlo, Nomy, Lemur, Kate Bornstein, Della Grace, [redacted] Molly Kiely, sara wolp Raine, HMC amputee support group, Tee Corinne, Tara.

91

[redacted]

Ring of Fire



THIS ZINE
PROMOTES
QUEER SEX,
GENDERFUCK
AND THE
ADVANCEMENT
OF
AMPUTEES
EVERYWHERE.

2

WELCOME TO RING OF FIRE #3

If you're wondering who I am, my name is HELLERY HOMOSEX and I am a double leg amputee. I lost both legs when trainhopping in 1996 when I was 18. Now I'm 21 and I just got new legs and am walking just fine. But it's been a challenging adjustment.

I bring this issue to you w/much pleasure because this one took me two YEARS to make!! this is the biggest zine I've ever done. I hope you find it informative, sexy + entertaining. FREAK OR BE FREAKED!

RING OF FIRE #4: THE MOTION PICTURE will be out soon (this fall). It's a video zine + I think it's going to be really cool. R.O.F#5, I'm hoping will include entrits from other people w/disabilities. so, if you're a crip, send me something!

AS USUAL I WOULD LIKE TO THANK some of the people who've given me deep inspiration + been my co-conspirators in subversion... thank you to the crips: LAYLA, NOMY, ROMHAM, AOISIN, APRIL, MIKE, DIANA, CHAR CURTISS, ALSO: FLY ✱, charlotte Cooper, D✱NYELL, AABL!!!! (the NW Network), LEFT B✱NK BOOKS!!!, Emma simon, karen Evler, my family, ELSBETH & DEVON, LEMVR♥, SACHA, MICAH, TERESA!!!, RAVEN, ZANNA, KALIAH, ketan, VAL, the ladies at st. pete's, SLOPPY FRE✱KCORE, RENO, ANGELO + ELLIOT, and everyone who wrote me about my zine. thanks so much!

KEEPIN MIND that this zine documents my ever-changing, growing + developing theories + ideas. so... ENJOY!!

(this zine is $1.50)

NOTE! NEW ADDRESS
po box 23036
seattle, WA
98102-0336

UNLESS NOTED, ALL STUFF IN THIS ZINE IS BY ME OR NOMY (fellow FOXY AMP VAMP)

XXX, HELLERY HOMOSEX
JULY 1999


BEHIND THE SCENES OF MY NOT-SO-GLAMOROUS LIFE...
I left my knee pads at my parents' house...
THIS IS A PROB-LEM
DISH SOAP
because I also need to clean both my pairs of neoprene sleeves. They are made of silicon and I must wash them every day because I wear them against my skin. They take several hours to dry.
PROS
of having the silicon sleeves vs. my old ones
+
CONS
easier to clean
new
old
they hold the sweat against my skin all day
which causes
skin break down
e-z to replace
less ingrown hairs
they stink
yew!
owl
owl
they're sleek and sporty
make my legs swell
4


pain
So, what do These facts have To do w/each other?
well, w/out my sleeves, I can't wear my fake legs, so I have to crawl. But w/out the knee pads it hurts my knees a lot. plus my hands aren't free to carry things so I slide them across the floor. It makes a mess.
I get:
callused, bruised, ache-y knees
OR, if I'm not x-tra careful I get raw bloody sores. mmm!
So, during the many hours I have spent on my knees I have developed a method of transport that is highly evolved. It takes pressure off my knees and simply requires sitting on my ass and propelling myself forward w/my arms.
It is v-e-r-y technical and cool-looking.!!! (*the patent on it is pending.)
HH 11/98
5

CRIP TALK

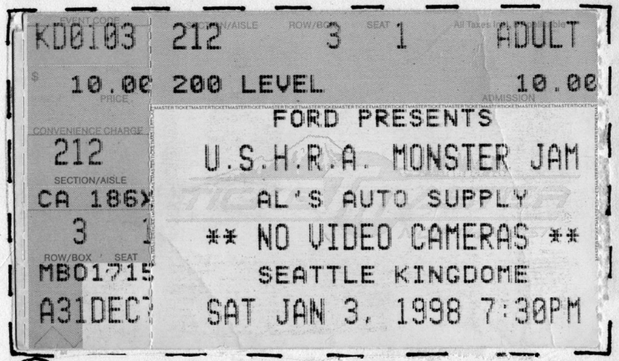
July 1998

With your host Hellery Homosex!

So, as time goes by and I make the transition from "new amputee" to "experienced amputee" I've had a chance to reflect on how differently all disabled people deal with their disabilities. And most of all I've been thinking about how we communicate to EACH OTHER about our differences.

Sometimes I meet other crips and it goes great. other times it goes not so great. I always learn something from it, though!

One time I was doing my volunteer shift at LEFT BANK BOOKS (support collective bookstores!) and I saw a guy in the back room looking at books and he was on crutches. Well, unfortunately Left Bank is not wheelchair accessible and we barely ever get people on crutches in there, much less other crippled Folks. I thought how funny it would be if he was an amputee and when I got a better look it turned out he was! He was missing one leg above the knee. I was pretty excited he was in the store so I decided if he bought something I'd tell him I was an amputee, too. when he came to buy a bumper-sticker I said, "Hey, I noticed you were an amputee. so am I."



⑥

I guess I expected him to say

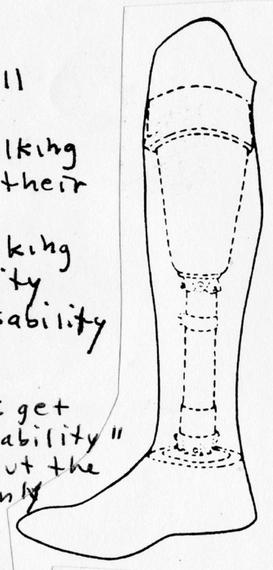
something like: "Oh, cool." or "Is that right?" but instead he was speechless. obviously this was something he did not want to talk about. He got really uncomfortable and the topic died. His wife tried to cover for him by chatting me up about my hair while I finished the transaction but things were tense and after they left I felt disoriented. I wondered if I'd handled the situation tactlessly. I'd felt like I did okay: I waited till he approached me, broached the subject, and quickly dropped it when things got weird. But it was frustrating to have our talk go badly.

These awkward situations happen to me somewhat often because of my willingness to connect with other crips/amputees/limbless people. I approach them about it and they go cold. There are many reasons why this could happen:

1. I'm too nosy/overbearing
2. they're shy, it's personal
3. they're a new crip - it's still touchy
4. they're not used to people talking to them so directly about their disability.
5. they are SICK of people talking to them about their disability
6. they can't accept their disability
7. I have bad breath

Then, there's other times where I get around those "overcome yor disability" type crips who never talk about the challenges of disability and only talk about how great they're doing. I can't really relate to them.

Or sometimes I get around a person,



Below-Knee Endoskeletal Prosthesis ⑦

or a group of people who have such advanced thoughts about disability I feel I'm lying in their wake because I can't keep up - they're so smart. Even though it's intimidating, I enjoy it because I feel challenged by new ideas.

Mostly though, my contact with other crips comes in two ways: 1) from my friend Nomy who is fabulous and talks with me about pus-y sores, and 2) from senior citizens who are disabled and tell me I "get along great on those things."



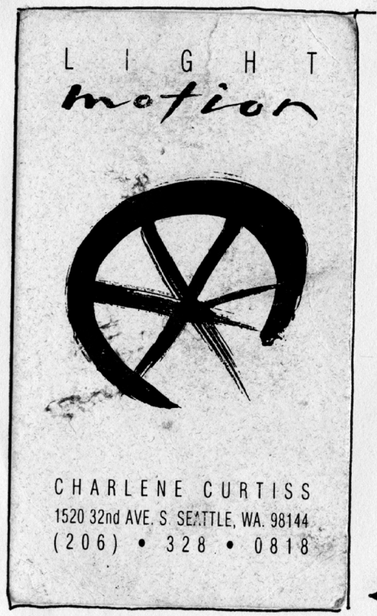
(8)

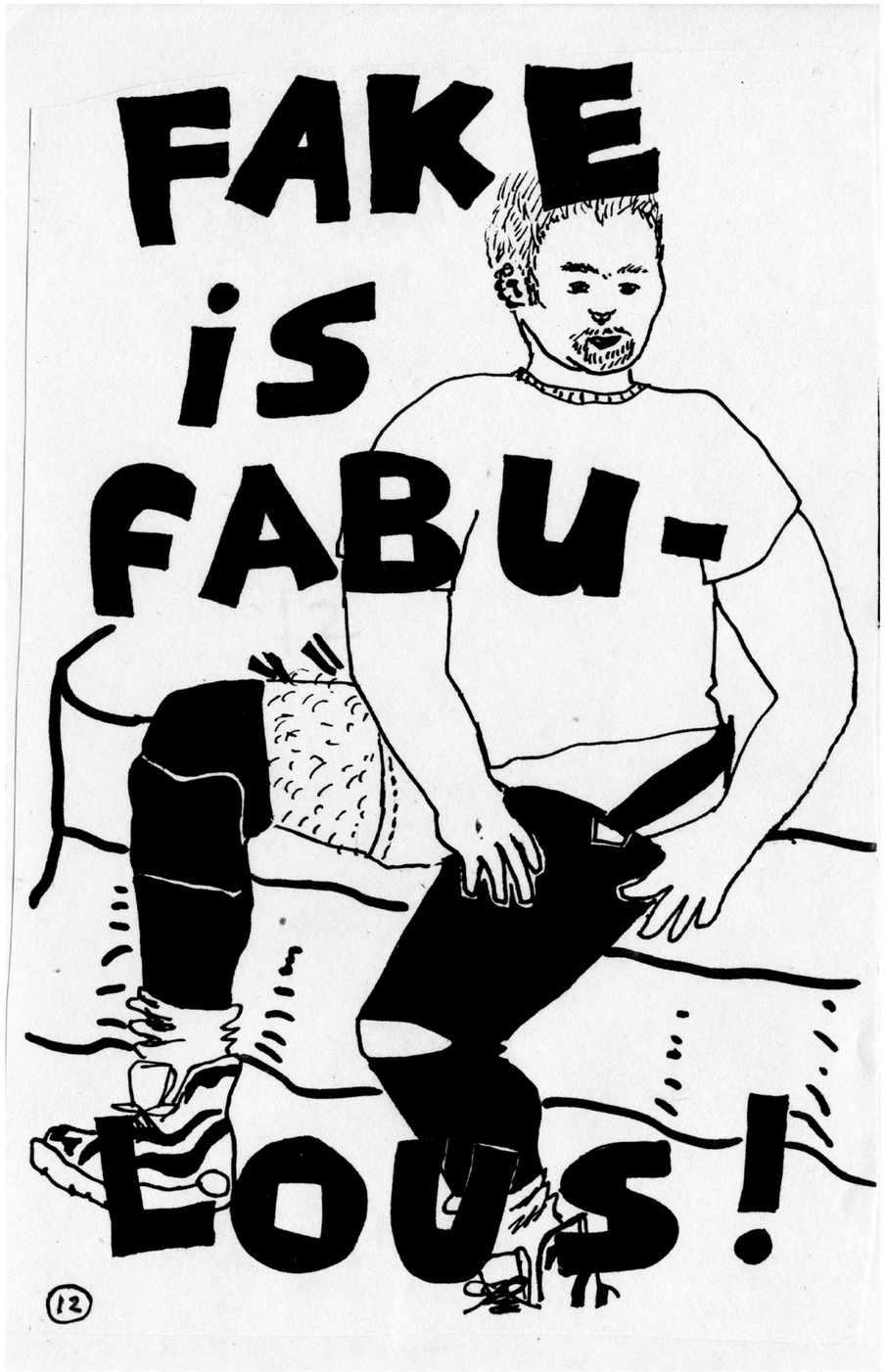
Wheelchair Performers Widen The Sweep of Dance Moves

If you want to see some really exciting new dance moves check out seattle's LIGHT MOTION dance company. Established in 1988 LIGHT MOTION was started by crips and non-crips to promote disability awareness through the arts. It's a company for crips and "stand-ups" (as charlene - the director - call TAB's) to push the boundaries of dance by working together and coming up with some pretty FIERCE MOVES.

LIGHT MOTION has performed all over the world (USA, Australia, Russia, Canada) and they do dance workshops, too. Charlene also teaches classes on wheelchair control at the U of Washington (the things she can do in a wheelchair you wouldn't believe!! she's such a stud + SO graceful!!) And she teaches general classes on wheelchair dancing. I took a few myself and I have to say it's a definite challenge.

DISABLED dance is something to take note of and support. you'll be glad you did. call OR WRITE LIGHT MOTION + GET ON THEIR MAILING LIST (9)



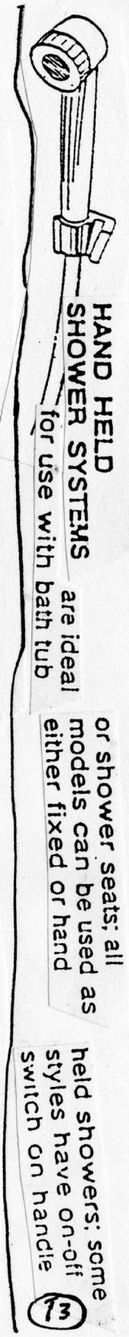


SOME THOUGHTS I HAD MAY 8, 1998 ABOUT CRIPS + CLASS ISSUE STUFF...

Disabled. Even thought I identify that way, it's starting to seem like such a joke to me. Like I've gotten past the point where I felt like I needed to talk about being an amputee all the time. And now I'm fucking running so I guess I feel less disabled . It seems like the only time I ever get to talk about it is with annoying acquaintances who don't really know me at all but the first thing they ask me is how I lost my legs. It's so annoying.

I was sitting outside school having lunch before my volunteer shift at the bookstore, when I noticed a homeless man come hobbling towards me on a pair of crutches. He had one leg and he was carrying a whole bunch of stuff in a pack on his back and as he got closer I could just tell he was coming over to talk to me about being an amputee. When he finally got to me he introduced himself and gave me a green plastic Mardi Gras necklace. He said you walkin' over here so good, an' I noticed your legs so I was tryin' to catch up with you to talk to you for a minute. He seemed real nice and it's practically never that another amputee will strike up a conversation with me, so I was pretty stoked about the idea of the two of us sitting down and having lunch together. Then, first off, he says he lost his leg in a train accident September 15, 1996.

I swear to god I didn't hear him right. What'd you say? you got run over by a train sept. 15th, 1996? I got run over by a train Sept. 14th, 1996. It was just the fucking weirdest thing. I haven't even known him two minutes and already he's telling me his leg got run



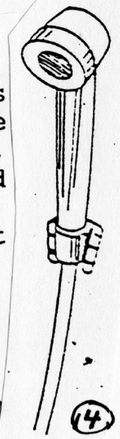
over by a train the day after mine were. It was the most eerie coincidence. My accident was in Oakland and his was in WA, but still... We sat and talked for about an hour, and he told me about how he'd been so drunk when he was on the train that night that he doesn't remember the accident even happening and he was in a coma for eighteen days afterward, laid up in Harborview Medical Center with a metal rod running up his spine, and his left leg amputated at the thigh. Craziness... Now he drinks all the time and he's homeless. He gets money from Social Security Disability (just like me), but he's so fucking lost and bummed that he spends it all on alcohol, and doesn't even wear his prosthetic leg because he has chronic sores on his residual limb from not being able to wash it on a regular basis. He asked me if I wanted to see his leg and of course I said yes, so he unwrapped it and underneath it was all bloody and raw looking.

SATURDAY, JANUARY 16 / 1999
At long last and to everyone's great relief, today brought news of the continued re-

covery from brain
surgery of beloved KOMO 4 news anchor a
of the newscasting universe, Kahi Goertzen. In a

We had a really great talk that day and every time we've seen each other since then we talk more, and it's really been making me think.

I see homeless amputees around Seattle constantly. It seems like they're always either trying to wheel themselves up crazy steep hills in downtown Seattle in inadequate piece of shit wheelchairs, or they're limping around on one leg and a pair of crutches struggling, carrying at least four heavy bags. I think about how if my friend could just live in a place where he could wash his leg every other day, he wouldn't have to have sores and infections on his leg all the time. Then he could wear his fake leg without pain and be able to walk on both legs on a regular basis.



14

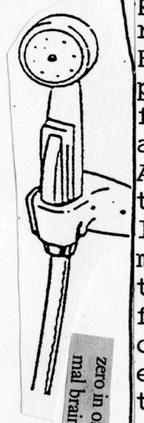
high-spirited personal e-mail posted this week on the KOMO 4 website, the divine Ms. G. revealed that

next week she will undergo radiosurgery to treat the tiny bit of tumor remaining in her skull. Using a device called a "gamma knife," surgeons will deliver a

high, single dose of radiation to the remaining tumor (computers and scanning devices make it possible to

I think about all the different kinds of disabled people I've seen and how money can completely change your quality of life. Yah, there's those amazing people who become disabled through some accident or disease and rise above their disability and conquer and everyone thinks they're so heroic. But if you look closely, a lot of the reason some of those people adjusted so well to their disability was because of money. Being disabled means having to use assistive devices to do the things you can't do. Things like personal aids, cars, manual and electric wheelchairs, prostheses, ramps, all seem like basic necessities, yet they cost thousands of dollars and are unavailable to a lot of disabled people that really need them. so, Christopher Reeve had a spinal cord cord injury, which is a truly difficult thing, but look at all the money he has. If he were an average citizen he wouldn't have all the fancy equipment, special care, and international support that he gets now. There is debate within the crip community about his fundraising efforts also. Seems like since the moment after his accident happened he has been trying to raise money for research to cure people with spinal cord injuries. For some people living with SCI this is a miracle: a celebrity, finally drawing attention to their cause. But other more radical crips are pissed off at Reeve for not accepting the fact that he'll probably be paralyzed forever, and for misdirecting his energy at fundraising a cure for SCI victims when really he should be promoting that the money be spent on better quality of life for the people that are already living with them. I definitely can see both sides, and I think that Reeve does have a

15



really special privilege in being able to use his fame to bring attention to people living with SCI, and that responsibility needs to be used wisely. But everyone has their own transitional process. Maybe he never will accept the fact that he's paralyzed, maybe he'll always be holding out hope for a cure. And maybe that's pathetic, or maybe that's what's giving him the will to live. I think he should do whatever makes it possible for him to make it through the day, and if that means fighting for a cure, well that's his choice. He's definitely reluctant to embrace the idea that he's disabled though, which doesn't help the crip community any. Maybe he feels like he's settling for less if he just fights for something like better quality of life for people with SCI, maybe that's not enough for him. But I wonder... Would it be enough if he didn't already have a bunch of money and rich celebrity friends in the first place? Maybe he just hasn't gotten to that point yet.

I've gotten a lot of support and recognition for how hard it was for me to adjust to becoming an amputee. But compared to other disabled people I had it so easy and I know that a lot of the reason why is because of money. If I didn't have a wealthy godmother who bought me a car I would have been even more depressed and freaked out then I already was. A rich friend of my mothers gave us several thousand dollars after he found out about my accident because he didn't want us to have to worry about money on top of worrying about everything else. Both of these things made dealing with the accident a lot less of a toll, and made my adjustment to becoming disabled feel like a lot less of a blow.

zero in on the tumor and reduc
mal brain tissue to the radiatio
and reduce the exposure of nor-
e radiation.) In the meantime,

Queen Kathi is enjoying spending time with her daugh-
ters (lucky, lucky girls) and is looking forward to

(16)

CRIPS + TRANNIES + MONEY #HIT...

I see a lot of similarities between disability and transgendered stuff in regards to classism. I hear a lot of trans people complaining about classism. In society you are not considered as being a transgendered person unless you've had sex reassignment surgery. Well, any trans person can tell you that SRS doesn't come cheap (they can run around $15,000 or more) and it is an INSULT to be told that you are not really a man or a woman just because you don't have the right genitalia, because often there are many people who WANT the surgery but don't have the MONEY to pay for it. So women's locker rooms that say you're only allowed in if you have a cunt are making a totally classist assumption that all trans people are able to buy surgery. It's the same concept for crips: a financially stable disabled person may be well-adjusted to their disability, but they have all the money to buy what they need so it's not impacting their life as much as it would someone who was in a different financial situation. It's the person with the money who gets the recognition (for being "Real" in terms of gender or being "heroic and capable" as a crip.)

"getting back in the swing of things!" perhaps as soon as the beginning of February.

PAMELA + TOMMY LEE ♥♥

LOS ANGELES — It appears **Pamela Anderson Lee** and estranged husband **Tommy Lee** signed away the rights to their sex video, so a federal judge said he will probably throw out their $90 million lawsuit against the Internet company that sold it.

The Lees contended they agreed only to have their explicit "honeymoon tape" relayed on Seattle-based Internet Entertainment Group's Web site, not for it to be distributed on videotape, CD-ROM and in hotel rooms. About 200,000 copies of the video have been sold, IEG said.

U.S. District Judge Dean Pregerson said Monday, however, that the actress and the Motley Crue drummer never asked for the return of the videotape, which they claim was stolen from a safe in their Malibu home.

Olympian news services

(17)


HH 1997
CUP-SIZED CORRUPTION
YAH, so I went bra-shopping yesterday and found out something horrible: I am no longer a 34B but a 34C !! Just when I thought my boobs couldn't possibly get any bigger I go up another size. FUCK !! out of all my body parts I struggle with my breasts the most. I want them to be small but they are big.
AAA 32
strapless
for a girl of small bust
COTTON FOR COM FORT
where'd they go ??
sometimes I smoosh them down with a sports brd. other times I bust out my Ace bandages and bind my breasts down as flat as they'll go. Large voluptuous breasts are supposed to be such a symbol of womanhood. But what happens when you have big boobs but you don't feel like a woman? can you not dress in drag? can you not be a man? can you simply not be a woman?
I try really hard to accept my body for what it is. One benefit to big tits is I can suck and bite my own nipples. mmm... As I find it easier to balance my male and female parts, it also becomes easier to take my breasts in stride. But it's hard.
18


NIPPLE PLAY MAKES ME WET
5/8
Getting my nipples pierced is another thing I've done to improve my connection to my breasts. I had both pierced several years ago, originally with rings, but now I have barbells. I barely notice they're there anymore, they're just part of me. But I can tell they're there because they make me feel sexier and that makes me like my breasts more.
14"
XXX
HELLRAY'S SEXY LIST 1999
-pamela + tommy lee
- shy tranny boy + boydykes
-blackberries
- femmes who dress in boy drag
- PUNK ROCK DRAG QUEENS
- people who are nice
-SCUMMY TWISTED PUNKS
- role-playing
-anonymous sex in public places
- transsexual voices
-public bathrooms
- FAG + DYKE LOVE vvv
- rocker boy tops
-AC/DC
- codpieces
- playing w/fag's nipples
-people who dance + talk a lot
-people who like animals
19

COURAGE

This notion that I'm courageous just because I'm an amputee is outrageous to me. I walk down the street with shorts on and strangers passing by on their bikes tell me how brave I am and ride away. I don't have to ask to know it's because I'm an amputee.

It stuns me. "What are they talking about?" I think. I mean really: what ARE they talking about? Do they say I'm brave because I am wearing shorts? Do they say it because I'm walking without crutches, or because my limp is fairly minimal? Or do they think I'm brave for the mere fact I leave the house every day?

When I was in my wheelchair it was different. No one ever told me I was BRAVE. people in public either didn't look at me at all (I was invisible), or they would say things like, "Do you need help with that?" or: "Here, let me do that for you (condescendingly)." But no one ever told me I was courageous. WHY? I don't get it.

Am I just easier to approach now that I'm not in a wheelchair: less like a "freaky invalid" and more like a "normal person"? Or, is it because I haven't tried hard enough to "overcome" my disability, and it's only when I'm walking that I'm inspirational.

(70)



cerebral palsy,

paraplegia

Women Seeking Women

spina bifida

I think it's a combination of both those things. There's this whole stigma attached to people in wheelchairs. When I'm in my wheelchair I become intimidating, and also I appear like "I'm not really trying."

THIS IS BULLSHIT.
The times when I'm in my wheelchair are usually the times I need the most support. Mostly when I'm in my chair it's because I can't walk. Either my legs don't fit or I have a swollen knee or a bad sore. These times are really hard on my self-esteem. I hate them. I hate them because they are out of my control.

I CAN NOT CONTROL MY DISABILITY.

That is what makes me so mad. I can not control if my prosthetic legs fit well or not. I can not control if I have an ingrown hair or a rash or an open sore. I can't control my pain or the fact that some days I have to use crutches or my chair. I have no CHOICE. And most of all, I did not pick to be DISABLED. I did not DECIDE to be an amputee.

I am not this way by CHOICE, although I am proud to be a crip. It happened to me and it was horrible and I lived. So now I go on with my life. But it's not because I'm some big, brave hero. It's because what the fuck else am I gonna do? Shrivel up + die?

(71)

ADULT HARD CUP WITH SUPPORTER

- Ideal for baseball, martial arts, hockey, and other high-impact sports

I leave the house and go through the motions. Sometimes I'm happy and sometimes I'm not. Whatever. BUT IS THAT WHAT BEING BRAVE IS? Existing? Is that what these strangers I meet in the grocery store think? that because I didn't end my life when I became a crip that I'm a brave person?

That's how it feels, and it's such an insult. It's like they want me to pity myself. I don't get it. they must think that being disabled is the worst, most disgusting thing in the world. Oh please! It is very challenging but IT HAS NOT RUINED MY LIFE.

obviously the general public doesn't know anything about disabled people (even though there's 49 million of us in the USA). So first thing they do is pity us, because they assume their lives are so much better. Alright, this can be overcome by education. Simple. talk w/ disabled people, get to know what they're like, find out more about them, cuz chances are that you or someone you know will become disabled some day.

SO PLEASE!! Listen to me (to all crippled folks) and tell us we're brave when we do brave things (we like that). But don't tell us we're brave just for the simple fact that we're crips. It insults us.

Pull onto Prosthesis

3.



Whether we get a physical disability during our life or grow up with it from birth, we too often find other people assuming that we are not sexual at all.

Apply Prosthesis Unroll other half onto Amputated Limb.

10/97

4.



LOOK DEEP INTO MY EYES

BY Hellery II "I love to shake my ass" Homosex 9/98

Look deep into my eyes.

No. I mean Deep.

Do you see. how I am a dude

Do you see secretly



LUBE

Even when I am the biggest girl I am still a dude. Like I'll just be sitting there having a sexy thought and my cock will JUMP and I know it is there. I am a dude when that happens.

MANY PEOPLE DO NOT GET THE PERFECT DREAMINESS THAT IS THIS REALITY.

Hi my name is chuck

Do you want to come play at my house anyways.

whatever person who can not see into my eyes. I am a dude.

But what if I feel like I am it. A boy.

you must not be looking.

dude that is a boys name. you are a girl.

that is wierd that is not ok.

No I do not. you are gross.

blechy-blech!

the main thing of being a dude is that to me it feels so right but to explain it with words can be very hard. So may I say RIGHT ON! POWER to ALL PEOPLE WHO are mixed up boyness and girl ness! groove on the magic of life

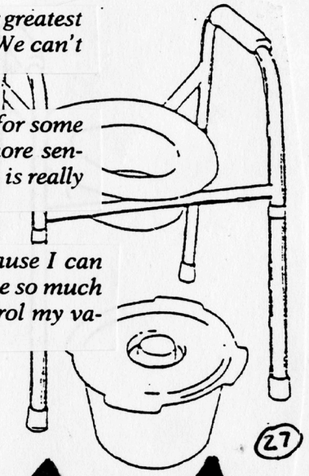


23

We don't do much "hard-core sex," but find our greatest fulfillment in slow, deep touching and holding. We can't seem to get enough cuddling.

I have no sensation below my waist now, but for some reason my neck, ears and armpits are much more sensitive than they used to be, and stimulation there is really quite exciting to me.

I really like going down on my partner because I can totally control what's going on and I experience so much sensation in my mouth, whereas I can't control my vagina or feel anything there.



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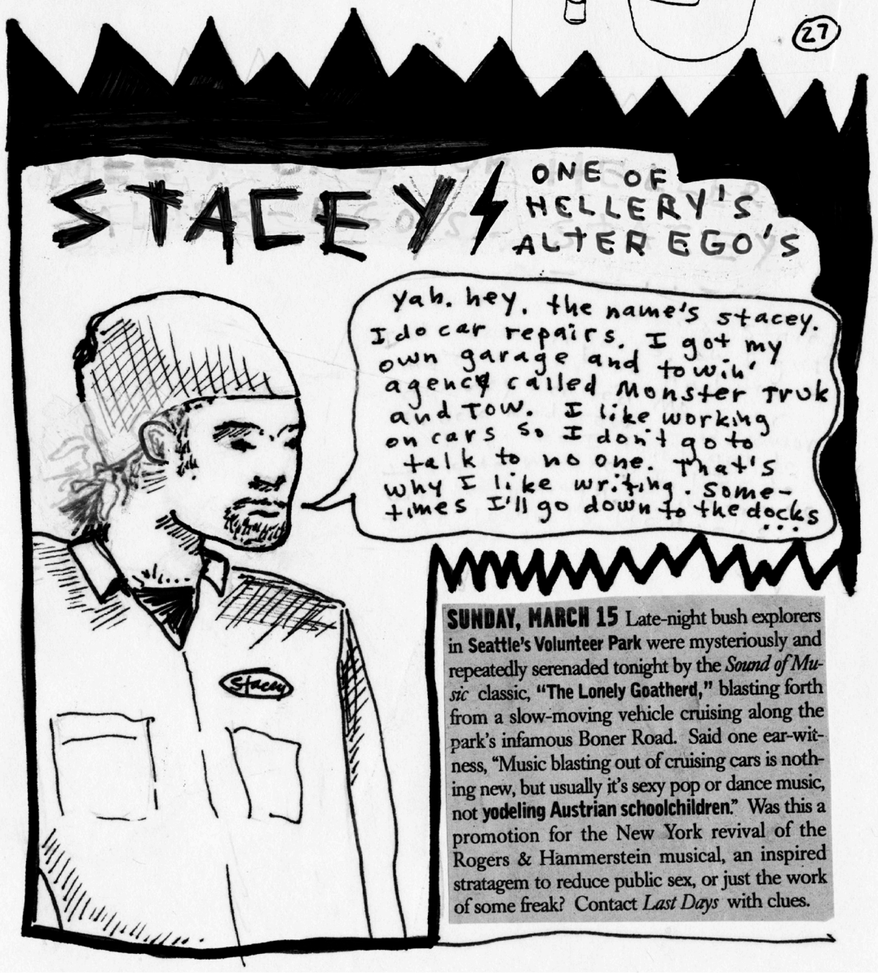


SUNDAY, MARCH 15 Late-night bush explorers in **Seattle's Volunteer Park** were mysteriously and repeatedly serenaded tonight by the *Sound of Music* classic, **"The Lonely Goatherd,"** blasting forth from a slow-moving vehicle cruising along the park's infamous Boner Road. Said one ear-witness, "Music blasting out of cruising cars is nothing new, but usually it's sexy pop or dance music, not **yodeling Austrian schoolchildren.**" Was this a promotion for the New York revival of the Rogers & Hammerstein musical, an inspired stratagem to reduce public sex, or just the work of some freak? Contact *Last Days* with clues.

MAN

MEN - MANLINESS - MANNISH - MASCULINITY - MAN HOOD - REAL MAN - LADIES MAN - MAN'S MAN

what is all this shit? All the time this is on my mind. I know I haven't talked a lot about gender fluidity in RING OF FIRE yet, but it's something personal to me and I think it's really important to talk about. Gender dynamics, I think, are a complex thing to wrap yr head around. Just even the concept of gender being a social construction is hard to remember sometimes. But as I examine gender more I am continually coming up with more ideas + questions.

OKAY, LET'S START OUT W/WHO I AM FIRST... I am a femme dyke but I am also a fag. This means that technically I'm a girl, and cuz I'm queer, a dyke too. But I am also into fags and into being a fag, and into being a boy in general. Plus I'm a femme so people percieve me as pretty girly. That can make things a bit complicated, cuz the way I see it I can still be a boy at the same time.

LAST FALL I WAS A BOY for about 3-4 months. I felt like a boy, I dressed like a boy and it was really hard for me. I needed my friends and lovers to understand, and most of them did - THANK GOD!! But not everyone, like my family for instance who couldn't figure out why I got so flat-chested all of a sudden, I wasn't about to explain to them that I was binding my breasts cuz they would've freaked out that I wanted to be a man. And the freaky part was I did want to

Boys Seeking Boys

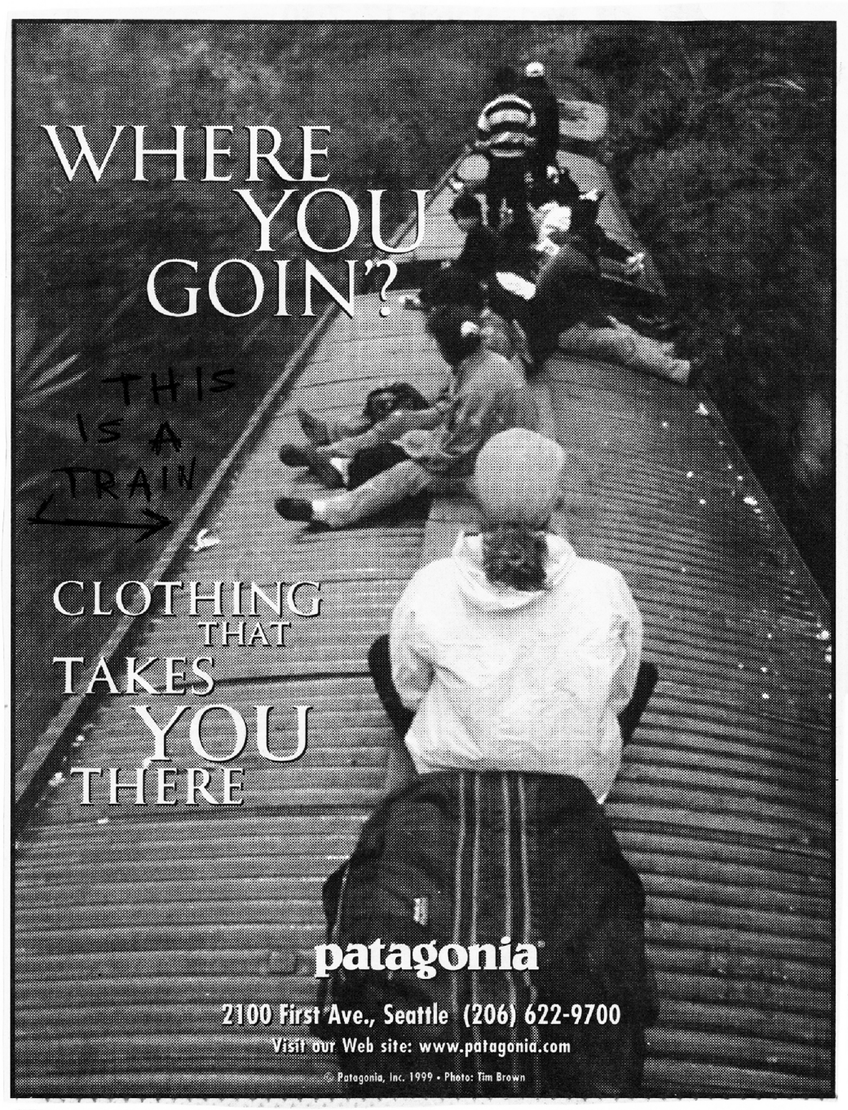
be a man. Or at least a boy. whatever I was, I was just not a girl.

That period of time was traumatic for me. I was possessed with hate for my body. I couldn't be naked. Ever. My reality was so fucking skewed cuz I just couldn't deal with it. I haven't been able to deal with tranny issues for several months now, and have been mostly living like a girl because it just got too hard. I've been happier these past few months and have been able to actually leave the house w/out wearing my binder. It's been a lot less exhausting not having to hate my body all the time. kind of like a vacation from dealing with it all. EARLY 1998

But the last two days I'm back to being a boy. Napping in the afternoon wearing my binder, a muscle shirt and my hair all tucked up in a trucker's cap. My new, fleshy cock + balls packed in my briefs. Happy boy, all cozy and asleep. There's many different parts of me and this boy part is one of them. -1999- Now I know I'm confused, and that's fine, because it's getting easier to find the balance between my different genders. Some days I am a man, or a young boy, or a woman, or a dog. It's all okay.

HH

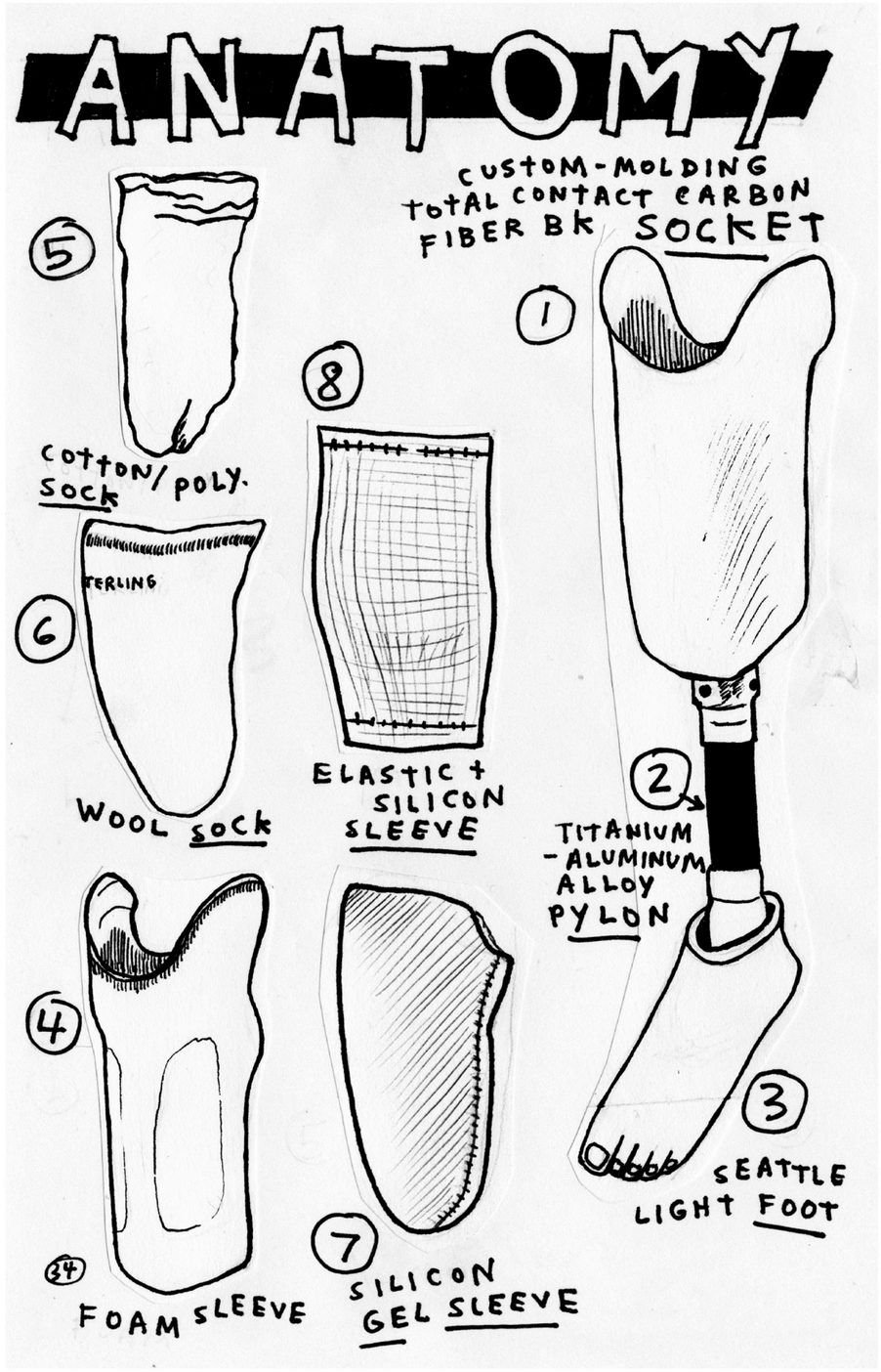




March 11, 1999 • SEATTLE WEEKLY •

I don't know if you can tell what this picture is but it's of a bunch of people sitting on a boxcar. WOW — PATAGONIA really has it's finger on the pulse of trainhopping fashion!!!! what a RE-LIEF. (yuck.)

30



OF MY LEGS

(1) The SOCKET is the hard shell that covers my residual limb. It is custom made to fit my legs only. My sockets must be molded to fit tightly because they are mainly what keep my legs from flying off when I walk. Average sockets need to be replaced every five years. (2) The **PYLON** is hollow light-weight metal like a bicycle and attaches the sockets to my feet. It is easily shortened to adjust height. (3) There are many different kinds of artificial feet, but I have the seattle light foot - a very basic, flat, non-bending foot. I do NOT have bendable ankles. (4) I used to have foam sleeves molded to fit my legs. I would put them on before I'd slide on my artificial legs. They were very hard to keep clean. (5) Before I'd put those on, I'd put on my socks: First, a simple cotton / polyester blend thin sock. (6) Then, I'd put on anywhere between one and four wool socks of differing thicknesses. (7) Now, instead of foam sleeves I have fabulous new silicon gel sleeves. They roll onto my legs and go right against my skin. They're so easy to clean, and now the wool and cotton socks go on outside the gel sleeves, and THEN I put on my artificial leg. (8) Once I get all that on, and make sure my legs are strapped in tight, I pull on my elastic (with silicon lining) sleeves that go over my knees and up to my thighs. The silicon helps them cling to my skin and attaches my fake legs to me to ensure even further that they won't fall off. **ALTOGETHER, YOU WOULD SAY THAT I WEAR "BELOW-KNEE PROSTHESES (pl.)."** or, as I'd say: "FAKE LEGS."
(pross-theeee-seez)

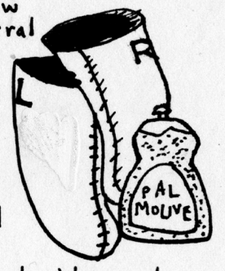

I WAS BORN ALL FUCKED UP
BY MOEY
BIG BRUISE
AFTER 48 HOURS OF LABOR, THEY FINALLY CUT ME OUTTA THERE. DR. SAID I WAS A GERMAN MEASLES BABY ...
HER LEG IS DEFORMED, AND SHE'S PROBABLY BLIND AND RETARDED. SORRY.
IT'S ALL THOSE DRUGS I TOOK!
WELL, I WASN'T BLIND OR "RETARDED" but the LEG PART TURNED OUT TO BE TRUE. XO
PLATFORM STYLISH, HUH?
MY FOOT WAS AMPUTATED WHEN I WAS three. I DONT REMEMBER MUCH ABOUT IT. JUST THE TERROR AND CONFUSION WHEN THE CAST CAME OFF AND I REALIZED MY FOOT WAS GONE.
TO TRY TO CALM ME DOWN, MY DAD TOLD ME:
I said:
DON'T BE SCARED, MOMY. THAT'S YOUR NEW FRIEND JOE. AND THIS OTHER ONE IS MOE!
NO, THIS ONE SHOULD be MOE, BECAUSE IT HAS A MOE (MOLE) ON IT.
MY "MOE"
AND SO... MY LITTLE LEG BECAME KNOWN AS "MOEY"
36


EVERY YEAR I WOULD GO TO THE SHRINERS' HOSPITAL TO GET MY LEGS MADE...
DURING MY 2 WEEK STAYS IN THE HOSPITAL, THEY WOULD KEEP ME IN A CRIB, LIKE A BABY. IF I WAS BAD, THEY'D PUT A HUGE PLASTIC BUBBLE OVER MY CRIB SO I COULDNT STAND UP.
MY LEGS LOOKED LIKE THIS
I HAD TO learn HOW TO WALK over and over again.
STUPID STUPID LEG!
I didn't HAVE A LOT OF PATIENCE.
but SOONER OR LATER I would FIGURE it out AND get used to it.
WHEN I WAS SIX, I SLIPPED AND FELL ON SOME WET GRASS, AND BROKE THE FEMUR IN MY MOEY LEG. BECAUSE that BONE IS SO SMALL, THERE WAS NO WAY TO KEEP THE BONE FROM MOVING WITHOUT putting ME IN A BODY CAST. FOR SIX WEEKS. LEARNING to WALK AGAIN after that WAS THE WORST. MY MUSCLES WERE LIKE JELLY.
MOST PEOPLE ONLY HAVE TO LEARN TO WALK ONCE.
NOW that I'VE stopped growing, I ONLY HAVE to LEARN to WALK AGAIN every FIVE YEARS OR SO.
IT STILL SUCKS.
FUCK! I FELL AGAIN!
37

A DAY AT THE PROSTHETIST'S OFFICE

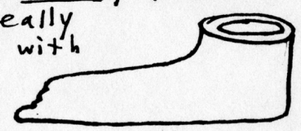
I was excited to see my prosthetist the other day because I had several problems with my legs I needed him to work out with me. Tami, the receptionist sat me in a room and Dale, my prosthetist came in and listened while I laid out the situation with him. "Dale, I am here for four reasons. I'll tell you the easy ones first. Number one is lotion. I haven't been using any with the gel sleeves and my skins been really dry. What should I do?"

1. The sitch is I've got these new silicon gel sleeves which have mineral oil in them that's supposed to replenish the moisture of my dry skin but it's not working. I want to put on lotion but it would get slimy on my skin inside the sleeves. He called the sleeve company and they said DON'T USE LOTION when wearing the sleeves. It'll get slimy + break them down. so my dry cracked skin will have to deal.

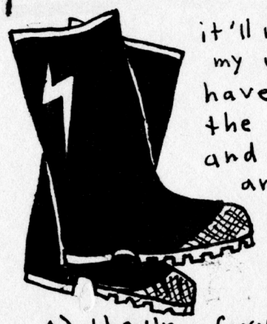


"Ok, so the second thing is insoles. I got some new boots and they need insoles."

2. I got new shoes which, to me, is a big deal cuz my fake feet are totally flat so I can't really wear shoes with heels on them because



SILLY ANARCHO FAG
Fun loving, sweet, dirty politico punk (27) looking to drink 40's, get tattooed, go dumpstering, make art, laugh, and revolt with other fags. Problem: I live in Olympia. But we can destroy Seattle together on the weekends. Friends? ☎ 3625



it'll make me tip forward all my weight, for which I have to bend my knees all the time to compensate and then I end up walking around with my butt sticking out which I hate. So I got new rubber galoshes, the benefits of which are:



A) they're foxy AND waterproof.

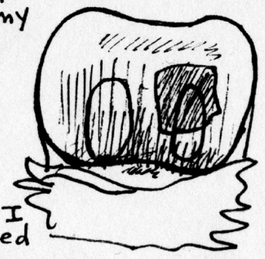
B) when I have them on, strangers can't tell I have fake legs which can be fun sometimes.

C) they're a soft rubber so even my stubborn stiff, unbendable feet can struggle into them.

But they had heels on them, so I cut them off and I needed to put insoles to balance them a little more, so he gave me foam ones. He said to get gel ones for shock absorption.

"Then, this padding on the inside is falling off and I have it duct-taped on."

3. As my legs change shape sometimes he gives foam pads inside my sockets to make a tighter fit. But now the pads were falling off and were taped inside. But randomly my leg fit just fine without the pad after he took it out so I guess I never really needed it after all.



"And the biggest problem is my left leg keeps falling asleep."

4. This one is pretty serious. If my leg keeps falling asleep that means its circulation is getting cut off and that is no good.

when I first got the new sleeves it took my legs three weeks to adjust (three weeks is my standard adjustment period). This meant using crutches to get to my classes at school, because my legs hurt, and during classes my legs kept falling asleep. After three weeks my right leg was fine, but my left leg was still chronically asleep, not just in class, but all day long, at home, in the car everywhere.

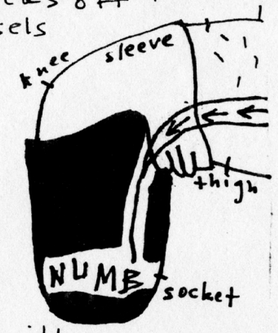
one time I sped all the way from the westside to the Eastside because the bloodflow to my leg was so cutoff my leg had gone numb and was starting to go cold. Talk about a FREAK OUT! I ran into the house, threw my fake leg off first thing and began massaging the feeling back into my residual limb. Ahhhhh... relief!

I had mentioned the problem in the past and he told me to go back to wrapping my legs at night with the shrinker socks and ACE wraps I had to wear the first six months after my amputations. Wrapping my legs keeps the blood from pooling and making them swell. So I started wrapping them every night which I HATE because it is A PAIN in my ASS, and it still wasn't helping.

I went to a play with my family and no matter how I sat I could not keep my leg from falling asleep. I clenched and unclenched my muscles, I tried every position possible, but it was just not working — so I had to take off my leg for the rest of the show (something I should not have to do).

so that brings me to my most recent appointment and he says maybe my new gel sleeves are bunching too much behind

my knees when I'm sitting with my legs bent. He says too much bunching blocks off the "vascular bundle" of blood vessels and nerves in the popliteal region (back of the knee) which supply my lower legs. The solution? He cut off a big chunk of gel sleeve so it wouldn't bunch and as far as I can tell it's working pretty good so far. A pretty simple solution to something that has really hard to deal with. YAY FOR PROSTHETISTS!!!!!!!!!!



APOTEMNOPHILIA

APOTEMNOPHILIA (Amelotation—loss of limb) Apotemnophilia (apo: away from; temp: to pull; philia: attachment to) describes people who are aroused by the idea of themselves losing a limb or having a body part surgically removed. Such people will occasionally injure themselves to an extent that requires amputation by a surgeon. However, most are content to fantasize about the loss as they masturbate. A few men crossdress as females and fake some sort of disability.

There are many theories for this behavior. One explanation is similar to that for why men cross-dress. As children, these men felt that females and amputees received special compensations. As adults, they prefer an unusual sex object or practice due to early-life sexual repression and guilt imposed by parents. They select safe objects for their lust. These may be prostitutes or a handicapped person. CAUTION: Actual removal of body parts causes personal disability and if it is done under unsterile conditions serious infections may result.

(See also ACROTOMOPHILIA, AUTOMASOCHISM, CICATRIZATION, DYSMORPHOPHILIA, MASOCHISM, MUTILATION, NECROPHILIA and TRANSVESTITES)

JAN 30, 1999

I WENT to the DOWNTOWN OLYMPIA LIBRARY + FOUND THESE 2 CRIP MAGAZINES:

"EXCEPTIONAL PARENT" at www.eparent.com and in print for parents w/disabled kids. It looked good.

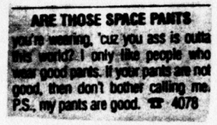
and "MAINSTREAM MAGAZINE: of the Able-Disabled". Despite it's unfortunate name this mag looked good, too. The seemingly historical "DISABILITY RAG" I've heard so much about seems to be long out of print, however.

DRAG. I've been doing drag on stage now for almost a year. And in real life I've been doing drag for about a year and a half. I like to do drag as a queen and as a drag king AND as a drag creature of WHATEVER (½-man, ½-woman ½-crocodile/pelican love child). But mostly I'm a drag king.

It seems like a lot of people don't really know what a drag king is. They know what drag queens are cuz they see them all the time: struttily their stuff down city streets, on stage at bars or in "Priscilla: Queen of the desert." All of a sudden RuPaul is a spokeswoman for ladies' cosmetics and everyone KNOWS what a drag queen is. But when you say you're a drag KING, people go "what?"

Being a drag king, to me, means that I dress up in exaggeratedly masculine clothes and act/sing/stumble around on stage in an exaggeratedly masculine fashion. It's very similar to the drag queen concept. But as I keep doing drag and going to see more drag shows I start noticing a certain pattern regarding drag kings.

Basically, there's barely any of us. At least in seattle. I've met a lot of queens, but the only kings I've met are my close friends who also do drag and either started getting into it at the same time as me, or were encouraged by me to start doing it. I hear stories about drag king shows that happen regularly in Vancouver BC and New York, but I have never seen them. It seems like seattle is definitely big enough of a city to have it's own drag



king cabaret, but for some reason it's like totally nonexistant.



DRAG IS WONDERFUL
DRAG IS GOOD- NOT EVERYBODY DOES IT- BUT EVERYBODY SHOULD

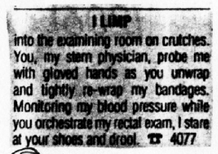
I think everyone should do drag. Drag is all about mixing it up. -switching genders, confusing genders, creating genders, redefining them and having fun with them. And it's FUCKING entertaining - that's fer damn sure! Not only is it a way to explore yourself and people who are different (supposedly "opposite" of you) but figure out a place where you and that opposite meet: your drag character. And it's also an underappreciated art form that requires a lot of work, talent, originality and courage. (props to Priscilla for winning best costumes in those pseudo film awards: the oscars*) I think mainstream society sees drag as a big joke "Hah hah! Check out dude in a dress!" and doesn't take it that seriously. For that reason, among others, I think that people who do drag need to be given support. From audiences and friends and also from other people who do drag. If this support happens then drag communities can develop and that is FABULOUS.

OBSTACLES TO WOMEN IN DRAG

Unfortunately not everyone gets support, and that is what I've been noticing lately. there's not all that many women who do drag, at least compared to men, and it really sucks!

I want to see more women doing drag, on stage or just dressing in drag in their day-to-day life. The few women I've seen who have done drag have totally rocked!! And I know hundreds more can rock just like them.

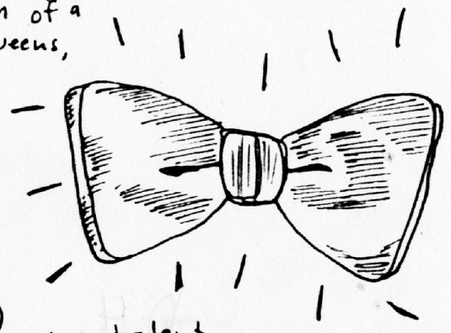
From what I've seen it doesn't take all that much encouragement to really get people started doing drag. Like I said, I haven't been doing it for all that long, but I've put on about three drag shows at this point, and the most recent one was last weekend and it was full of women doing drag. It was so fucking great! There was fag drag, and dude drag, astronaut drag, little boy drag, Pee wee Herman drag, alligator man drag. It was all really creative and sexy and fun. And there were drag queens too and drag queen/king mixes and trannies in drag and it all complimented each other so well. It filled my heart to see everyone: boys, girls + trannies on stage together. But the kings were in full effect, and it blew my mind because I didn't have to beg + plead + shove + urge them all on stage either (like the first few shows). They performed willingly and confidently. All they needed was for someone else to pave the way a little bit and they revealed themselves. And that's just in my little town of Olympia, too. I imagine what could happen in a big city like Seattle...


I LIMP
into the examining room on crutches. You, my stern physician, probe me with gloved hands as you unwrap and tightly re-wrap my bandages. Monitoring my blood pressure while you orchestrate my rectal exam, I stare at your shoes and drool. ☎ 4077

MISOGYNY

Something that is really tearing me up right now is the division between gay men and dykes. Of course it's always been

there, and I hate it, but the queer community isn't the utopia we may like to think it is (immune from sexism and gender roles that are fucked up.) It makes me really sad but it's staring me in the face: the gay world is so fucking full of misogyny (woman hate), and it just makes me sick. With the exception of a few amazing drag queens, most fags who do drag could give a flying fuck whether women do drag or not. They just do not give a shit. They seem to think women who do drag are boring and have no talent.



Well, obviously I disagree with them, so why do I care what they think? I don't care what they think - to a certain extent. I'll do drag no matter what - even if they ignore, patronize me and yawn through my act - I will never stop doing drag. But I do care because it sucks. I love gay men and I love drag queens and it's fucked that so many of them don't support women.

It makes me really angry sometimes because I just feel like they've already got their little drag scene all set up real nice and don't give a shit about the women that are still struggling to even get started. Especially since I know it's not all that easy to be a drag queen. They have to earn their respect just like the rest of us - so you'd think they'd understand, but they don't. I feel like it so much has to

do with male privilege, and the attitude of "As long as I have what I want, everyone else can deal with their own fucking problems." It makes me upset to say it but because of the way society has been set up, men have the privilege to not have to reach out to others because society is already set up to accomodate all their needs. I see gay men abusing this privilege by not supporting women in drag.

women can get by without male support. The dyke community is pretty fucking supportive in a lot of respects, and it's not too hard to get encouragement from other women for doing drag. But it would be NICE to get encouragement from the queens because they already have a strong drag scene set up and they have experience that us kings could learn from. It would be great if we could all work together.

RUN, DON'T WALK, TO YOUR NEAREST WIG SHOP!

so basically I think more women should do drag, and I wish they would get more support to do so, especially from drag queens. This can be done by open invitations to women (specifically) to perform in drag shows, and in other enumerous ways, like kind words, sharing tips and performing together. LET EVERYONE PERFORM TOGETHER - women, men, traunies, and all the lovely in-betweens ♥ - !!!! (Also, I'd like to add that women can be queens and men can be kings and it's all up to you to be all you can be ♥) ## 11-98

(46)

A FEW WORDS ON LIMPING
July 30th, 1997

Some days I don't limp at all, and other days all I can do is limp. It seems like my limping days are getting less and less as I get more used to my prosthetic legs. When I limp now, I really notice it. Sometimes I hate myself for limping. "What? Can't you fucking walk like a normal person?" Sometimes I get so fucking irritated with myself for being crippled, like it's a sign of weakness, or that I'm stupid if I limp. Sometimes I hate other crips for limping. Like they're so fuckijnjg obvious and can't they just stop it for once? I feel bad when I think that, when I think badly about other crips, cuz I'm sure that's how most of able-bodied society thinks, They just want crips to remain invisible. I like to think that as a crip myself, I am immune to those thoughts, but sometimes they just happen. I know I'm just imposing my self-hate onto other people, but it's kind of freaky to admit. I'd rather not limp. But most of the time I have no choice. It's what my body does. I just need to get used to that.



LIMPING

I probably limp about 80% of the time that I walk, even after 2 1/2 yrs. Most of the time my limp is slight and may just show itself as stilted walking since I have a limp on both sides. I still really hate limping sometimes, just cuz it sucks, but like so many other things regarding my disability I have become accustomed to it. Eroticizing a limp can be fun and I have come to fully appreciate the very sexy limps of my AMP VAMP friends Nomy + Layla



I Hate ROADKILL. I freak out when I see road-kill on the highway. Flash of flat bloody dead animal as I drive over it at seventy miles an hour. Jesus Christ I see myself. I'm screaming in my head and In the privacy of my car driving as fast as I can like I can get away from my flashbacks. make it stop make it stop. How do you keep control of a car when you can't open your eyes because you are so scared? It's not like I can just not go near freeways for a while. The reason I drive and have a car now is because I'm disabled. Why am I disabled? Because I got run over by a train. But now almost every other day that I drive I see roadkill in the street and there I go having another flashback.

It's not like I'm kidding myself or anything, but when I started walking again it was almost like I could forget that it ever happened. If I wore pants over my legs I could forget that they were made of metal and plastic. I knew I'd never forget the train accident but I figured maybe I'd be able to have a break from thinking about it all the time.

well, in a way I kind of have. Strangers in public places don't come up to me and ask me what happened so much anymore (thanks for the concern you nosy insensitive assholes). But now that I 'm starting to have a life after the accident I wonder if I'm more ready to deal with the flashbacks, and that's why they started happening again. Like somehow my mind knows I can afford to think about the past without totally losing it.

But that doesn't make daily panic attacks in my car any better. I think holy shit holy shit if someone else were here with me they would calm me down, tell me a story, sing to me, tell me when the lanes were clear so i could get off the road. All I can do alone is just speed up too fast to get farfar away. I HATE ROADKILL I HATE DRIVING I HATE BLOOD

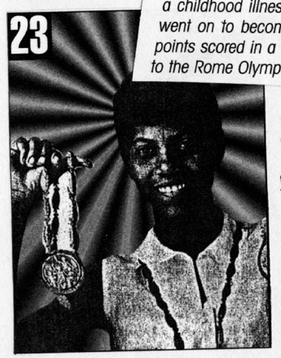
51

I HATE BODY PARTS I AM FREKING OUT every time I see a dead animal run over I think I am like them. I know how they feel. I hate that.
8 7 97

THE TOWN WHERE I LIVE.
In the town where I live are many great things: collective cafes, good friends, a friendly activist community, and lots and lots of drag shows. But there is something else in my town which I do not know how I feel about. There is a train that runs right through downtown almost every day.

The train moves slow and no one else thinks it's scary so is it weird that I do? What if, I think I think, a kid run out into the street and got hit by it, or it was night and you turned your car onto it's street without seeing it. Today I was driving home on 4th and it was crossing. I was the first one to it and I sat there in my car as it drove by with my eyes shut singing to the radio. I drove away singing and repeating "don't think about it".

I don't flinch at roadkill so much anymore but the train went by today, two years and four months afterwards, and I didn't like it.
1 11 99



WILMA RUDOLPH

23 - WILMA RUDOLPH

(b. June 23, 1940 d. 1994) FEBRUARY 23, 1962

Wilma became the first African American womyn to be awarded the James E. Sullivan memorial trophy as outstanding amateur athlete of the year. Because of a childhood illness, her left leg was crippled and no one expected her even to walk. She went on to become a basketball player setting a state record in Tennessee for the most points scored in a season. Undergoing a major illness and surgery, nonetheless, she went to the Rome Olympics where she won 3 gold medals, setting an American track record.

whenever someone gives me a calendar I always check to see what the picture is for my birthday and if I like it, then I know the calendar is all-right. It's picky - I know. But when FLY sent me the SHEROES calendar WILMA RUDOLPH was the hero on Feb 23rd. Foxy, huh?



I had to be alone with it so I could see myself in the mirror as I'd been picturing myself for SO long

binder

NOT 20 MINUTES later I was trying it out to see how it worked

fake legs

dildoes = dentures =

but it was SO WIERD!! I was finally getting to fuck someone with a dick. It had been my dream for so long, and now that it was happening, I COULDN'T FEEL A THING !!!!!.....

54

IT WAS JUST LIKE WHEN I LEARNED TO WALK.

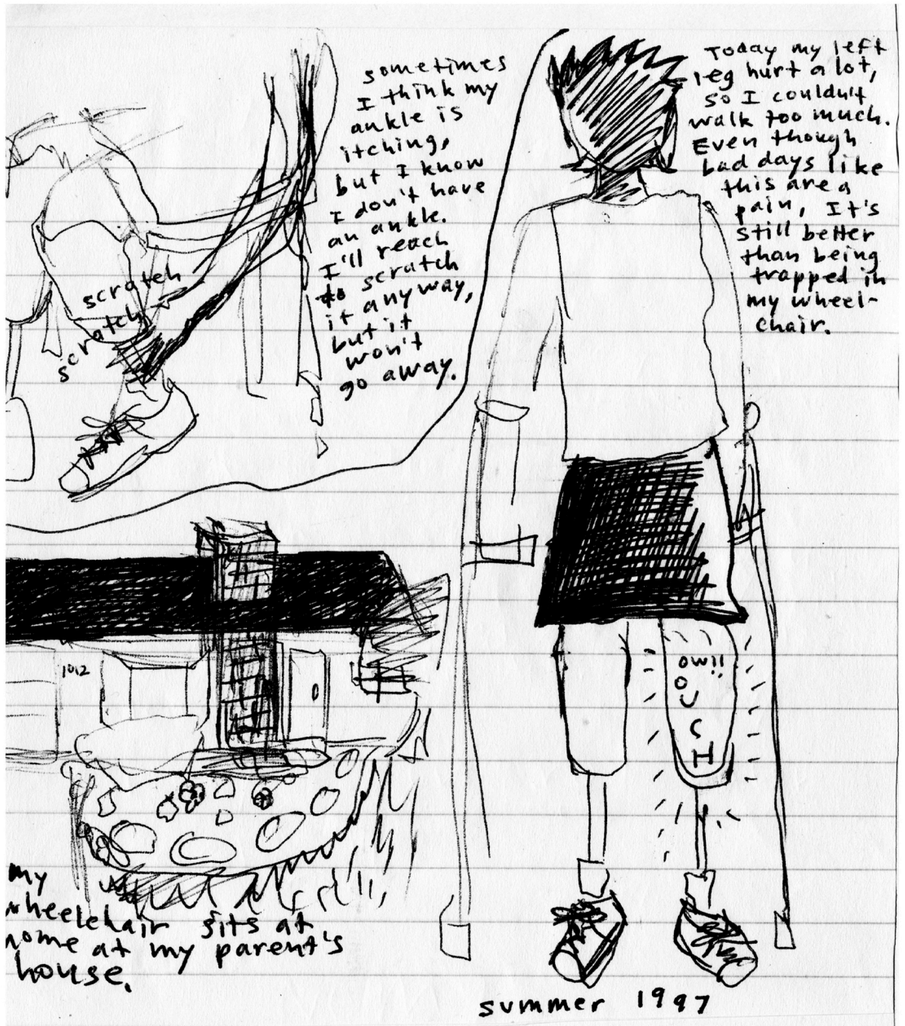
I couldn't feel the ground as I was walking. Like both my Feet were asleep but I had to walk on them anyways. Fucking with a dildo WAS JUST LIKE THAT. my body was inside of him but I feel couldn't it.

ghost feet

NOW I've got **three** prosthetic appendages!! LET'S SEE if I can set a WORLD record !!!

THE END 8-98

55

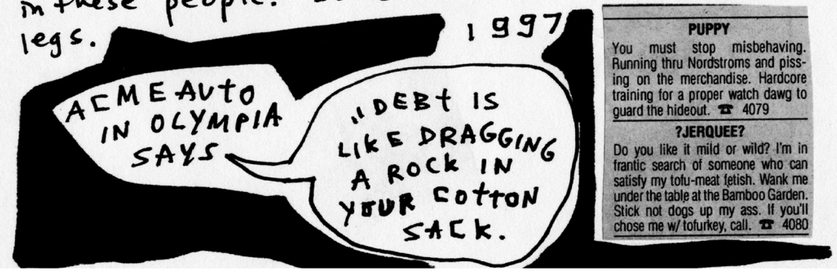


Sometimes I'm scared to take my legs off at night because I don't want to look at the real legs (or lack of) underneath. I have the luxury some other crips don't: I can fake it. When I freak out and

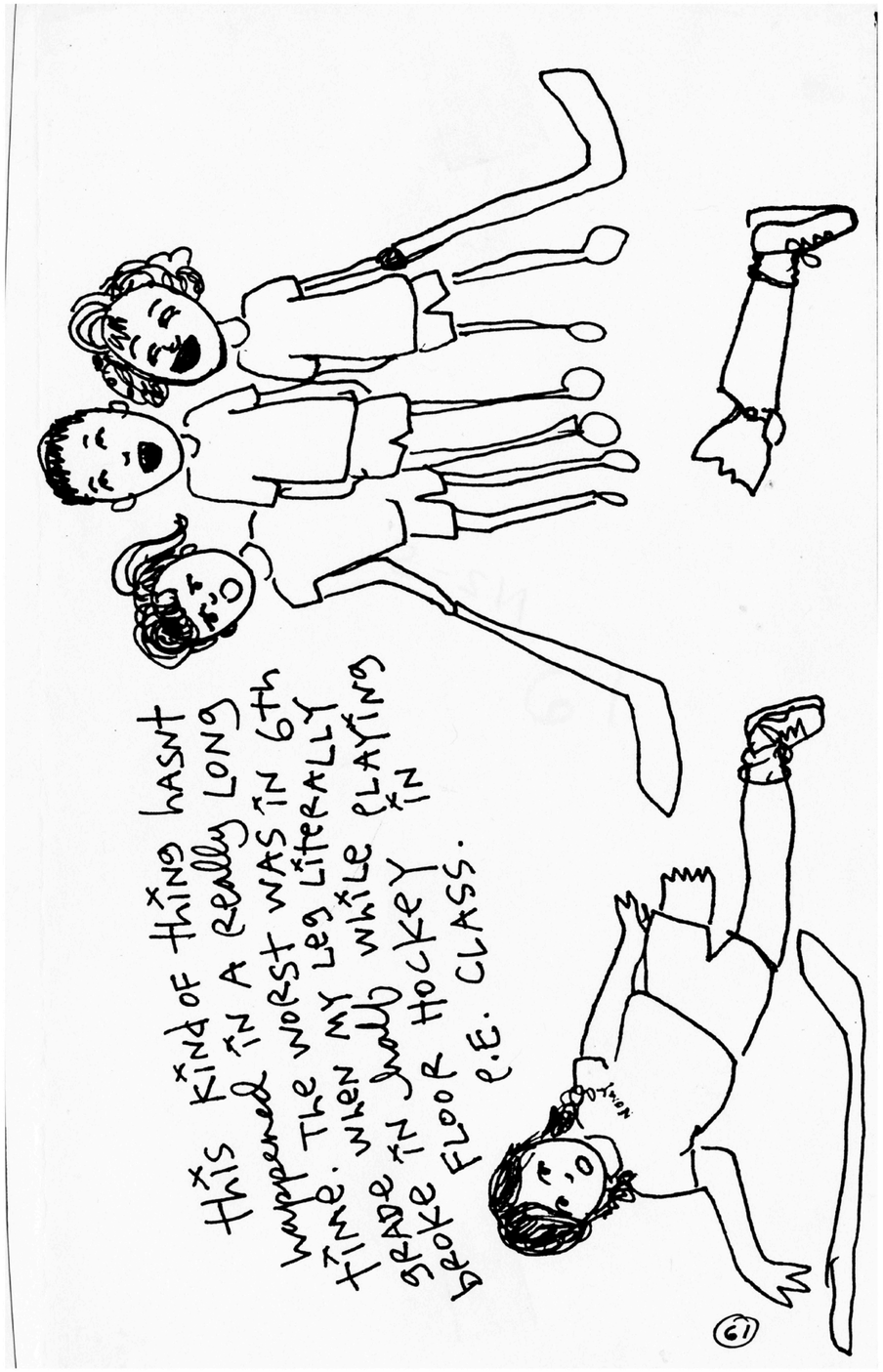
have flashbacks and feel like my body is falling to pieces, I can just look down, see two fake feet and feel fine. It doesn't matter they're not flesh. Just the fact that I still have feet matters. That when I reach down to grab my ankles I'm not just grabbing the air. I don't care if they're metal. It doesn't matter; I just need something there. Something.

But when I shower I have to take off my prosthetic legs and I have no choice but to stare at, touch and watch what my legs have become. Pale, sickly, white, hairy stumps with bruises and sores, pus and red bumps. Now - I love the crip community, we are strong and resourceful and I know we are beautiful. But sometimes I have a goddamed hard time finding the beauty in pus + blisters. It's a self-hate thing. I know. I need to learn to get over it. I'm working on that.

But now I'm noticing other things. Sometimes I'll see a picture of another amputee and I'll have to turn my head away in disgust. "I know what her legs look like under those plastic casings," I think. "they look like mine and they're ugly." I get so worked up sometimes, grossed out, pissed off. It's only because I see myself in these people. sometimes I hate my own legs.




FUCK!
MY LEG
IS
BROKE!
BY
NOMY
LAMM
60


THIS KIND OF THING HASN'T HAPPENED IN A REALLY LONG TIME. THE WORST WAS IN 6TH GRADE IN JUNE WHILE PLAYING HOCKEY IN P.E. CLASS.
61


I used to break my fake leg ALL the time & I'd have to go to school on crutches. It didn't really bother me. I could go super-fast on crutches, like those big tall rabbit creatures in The DARK CRYSTAL.
G2


Of course it had to happen in public.
WHOA.
I'm okay. Just leave me alone for a minute. I need to think.
well this is a change of plans.
G3



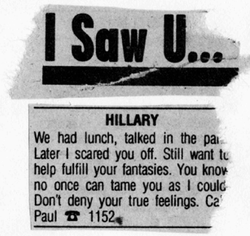
"ANNIVERSARY? -WHAT?"

BY Hellery
"I-love-Lynda-Barry" Homosex
sept. 15, 1998

yesterday was the two year anniversary of my train accident and I completely forgot. I didn't even realize it was the fourteenth until me and my roommate were watching the simpsons and he asked me how the Anniversary was going. uh, duh. that was my response.

Last year when my first anniversary came I was freaking the fuck out. I planned for a month-and-a-half what I would do on "the day." I spent a week gathering supplies: firewood, spraypaint, journals, books, sex toys, cds, tapes, records, clothes, costumes, oil pastels, papers and markers. what I didn't have enough of, I bought. I headed off to my friends cabin for four days with a station wagon full of shit just for me. I painstakingly made sure I had everything I might possible need to make sure I didn't have a complete and total breakdown the day of.

I had no idea what to expect. I was really, really frightened I'd relive the whole experience over again, be too weak to take it, and have a complete emotional attack while secluded in the woods. I brought with me the little journal I had in which I'd documented every little detail I remembered about getting run over. I hadn't read those entries since initially writing them and I thought I might want to on "the big day."



I talked a lot beforehand with my friend whose mother had died suddenly. she had some really good advice for me on how to deal with anniversaries of

65

tragical events. Mostly she made me feel like I wasn't alone, and I was glad she understood how big a deal the first year marker was.

By the end of the first year I was walking, I had a car, and I was about to start school. Other stuff was going on, too. Like I started doing drag a lot, and acting like a boy. It was really confusing. There was a lot going on. But mostly the first year anniversary was important because it was like, "Man, it's been one whole year where I haven't had any feet." Kinda freaky, huh?

so the day of september fourteenth 1997 I was prepared for anguish, but actually it wasn't so bad. I think I wrote a lot of letters and ate food and stared at the river and it was pretty peaceful. I remember, though, falling asleep that night and being really relieved that it was all over. I never could read through that one little journal where I wrote the hard stuff down. I still haven't touched that one.

I was fine at the cabin alone. It was the next day when I came home and had to deal with reality again that I fell apart. But I felt really good about the anniversary. I felt like I'd really honored it and I was glad I'd spent it alone. surviving it made me feel brave.

But this year I don't have to worry about survival. I walk just dandy, I have my own house, my own life, I am self-sufficient. I am happy, and right now I am most concerned with staying that way. So I haven't really wanted to acknowledge the

CUTE RADICAL ORGANIC GIRL
eating home fried potatoes at Black Cat Cafe. I was redhead boy with up ring and bike clothes. Would like to see you around there again and ride critical mass or find me puleez.
☎ 1461

anniversary because that would mean re-experiencing the accident in some way, and I don't feel like I need to do that. But to go so far as to completely forget it— that surprised me.

Another friend whose brother died when she was young said sometimes anniversaries are really hard for her, and sometimes they are easy, and you can never tell how it's going to be. Sometimes you relive it all over again. I don't know if it'll be that way for me or not. She said she never really dealt with her brother's death because she was so young. So for her, she's still carrying it around. whereas, me, I feel like I already dealt with the accident really well. who knows? I'm sure there'll be some years that knock me down on my ass and I'll just have to handle them as they come.

One thing I did to empower myself about the accident was get tattoos with my friend Cooter, who got hurt in the train accident with me. I got a big, blue lightning-bolt/scar scrawled on my right ass cheek and she got one on her calf. It was like we swapped the scars we had in real life. I love my new scar on my ass. It makes me think of Cooter, not as something scarred like a victim, but as someone who flaunts their scar as a form of empowerment. Celebrating the scars like they are beautiful makes me feel like a superhero. Fuck yah!!!! cuz I am !!!

this is probably the worst ad I ever read. I've had it in my wallet for a yr.

WHITE SOFT BUTCH
seeking black femme. Me: W, attractive soft butch, 5'4", HWP+, kind, honest, 45yo prof. Interests: golf, fishing, travel, movies, music, dancing, coffee houses. Lt. smoker, lt. drinker, no drugs. You: Black attractive femme, 35-49, career-minded, HWP or HWP+, no HWP++, similar interests, honesty a must, no drugs.
☎ 1423





STUDY BREAK

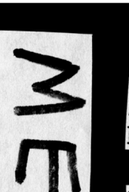
I've got two hours before I need to be anywhere and I should study but instead I open my dresser drawer and pull out my toy bag. I grab my harness and strap it on cuz it's been awhile and I really want a cock between my legs. I pull out my realistic cock and balls and slide it into the harness, rubbing it against my pussy before shoving it through the O-ring. Just the thought of getting fucked makes me creamy and the cock comes alive for me as I run my finger along it's sensitive tip and hump the covers of my bed, hot for some cunt to fuck. In reality I'm all dressed up in my sluttiest girl clothes in the privacy of my bedroom, but in my fantasy I am a he, and you and me are in a video booth at the local porn shop. You are the sexiest fucking woman — definitely a woman but you also fit so easily into my man-on-man fantasies cuz yr also a really hot guy. I slip the cock out of the harness, cover it with lube and bring it behind me to rub against my pussy. The rubber is cold, so I rub my clit with it to warm me up while I slip a couple fingers in my cunt and push in and out. It feels so good I stick the cock in and clamp some clothes pins on my nipples. mmmm... which are jutting out in front of me on account of my dress

being pulled down in front. The heat and pain from my nipples shoots straight to my cunt which I'm fucking with the cock. My cunt starts feeling so loose and crazy my legs begin to slide apart. I want more, more. My fingers grab for my clit and rub in slippery lubed circles, the cock is sliding in and out behind me, and I struggle to keep balancing myself on my knees on the bed. My clenched thighs make my cunt even more tense so I reach for my butt plug, lube it up and start fucking my ass with that in the right hand and the dildo in the left. My cunt and ass are so full it's got me in a frenzy, but all of it is being channeled into the cock I feel standing straight out in front of me. You're leaned over the video screen while I pull down your pants and grip your hips hard. I search for your asshole with my tongue. I can smell your cunt from behind as I rim your ass, you are so wet, you start to moan so I kick you in the calf and whisper to shut the fuck up. I unzip the front of my coveralls and pull out my cock. I slide a lubed condom over it and when I find your cunt it eases right in. Even though you're silent I can tell it's right and I reach around you underneath your t-shirt and slide my fingers through the lips of your cunt, gently circling your clit and I fuck you hard from behind. My hips banging against your skin as our sweat soaks all the clothes in between us. At home I circle my own clit feverishly as I fuck myself from behind seeing nothing but yr sweaty back in that fluorescently lit white booth. As you cum an orgasm shoots through me and my thighs go crazy as I collapse on the bed.



M.E.

AUTOFELLATIO Autofellatio is performed by a male on himself.



A whole year I've been trying to write this and it's never worked. I think it's finally starting to make sense, so here we go: WHY I AM GENDERFUCKED.

The first night I did drag changed my life. They were having the PIRATE PROM at the pirate house and my date was the PROM QUEEN. Everyone was running around the house getting dressed while I hid in the bedroom with my white gloves, pretty-in-pink ball gown and matching powder pink nail polish in my lap. I had bought the dress especially for the prom because I'd never actually gone to my real high school prom. But as I watched all the other femmes running around doing their hair and prettying themselves up I started to get depressed. I sat there with my dress in my lap unable to start changing my clothes. I REALLY started to feel like I didn't want to wear that pink dress anymore. I didn't think I even wanted to go to the prom anymore. All of a sudden the idea of that dress became trap. All I thought about was how I couldn't be like those other girls: all dolled up. All I wanted to do was wear the men's clothes I already had on - work pants and a cowboy shirt. And that's when I knew: what I secretly needed that night was to be a boy. It was such a fucking relief to figure it out all my feelings about the party changed and I ran into the bathroom.

While all the other girls finished dressing I stood in front of the bathroom mirror getting ready. I took the Ace bandages I wrapped my legs in at night and bound them around my chest. I took eyeliner and covered myself in facial hair then I slicked back all my hair with pomade until the [redacted] dude I saw in the mirror reflected the one exploding inside of me.

I picked some name, I think it was Hank,

Months of depression and confusion had led me to that party. My boyfriend was a fag, I was a dyke and I was also a recent amputee. I had a lot of confused emotions stirring in my heart. I struggled to deal with them but I just couldn't keep up with it. My body image was fragile and I was really confused about gender. But as soon as I painted that facial hair on and wrapped those Ace bandages around my chest it was like this humongous part of me that had been bottled up inside was finally able to come out.

I did not break character for one split second. It was way beyond just my outfit, it was my speech, body language, everything.

I moved like a man and I felt my body change. My chest flattened, my cock hardened, my muscles developed. My voice grew deep.

‡It is ironic that with most physical disabilities we are considered asexual, yet if we have a condition which makes us appear unintelligent—mental retardation, emotional or speech disability—we are often thought of as *overly* sexual. For instance, one argument against sex education for mentally retarded or

ANAL SEX



Sitting on the dimly lit porch my old friends didn't recognize me. My prom date said she really felt like I was guy. I felt like I was a guy. And I was really fucking happy. I felt like I'd discovered a whole new aspect of myself and found some peace within me, too. Once I stumbled onto that character, for the rest of the night I could not break out of it. I was so focused and involved in being Hank, and once I began it just seemed to carry itself through the rest of the night.

That was when I first met the dude that was inside of me. I liked him and I wanted to feel that feeling of expressing a new gender more. That night changed my life because not only did I realize I had more than one gender inside me but I also figured out that I had a way to express those genders positively. I have done constant gender discovery and experimentation since that night, playing with my many different creatures. Hank hasn't appeared again, but the gnarly dude that he inspired shows itself under many different names.
9 1 98

deaf people has been that others didn't want to encourage their "natural promiscuity." This reveals an odd warp in our society's assumptions about sexuality.

CRIPS ON FILM

JAN 1999

The release of the horrendous-looking new Val kilmer Film: "At First Sight" spurred me to have my own disability movie film fest. Admittedly I have not seen this new movie but it's plot repels me: blind man played by Val kilmer gets a "magic surgery" that enables him to see for the first time + he falls in love with pretty girl Mira sorvino. My reaction to this film is BIG WHOOP! It's so hollywood syrupy that any respectability about it seems lost but what bothers me about it is why a fluff movie like that would get so much publicity while any decent films about disability are never seen because they get such low budgeting. *Most blind people do not get magically "cured!" this film is not representative.

at first sight

an amazing true story

In search of other crips films I started with a few basics and rented:

"CHILDREN OF A LESSER GOD" 1980's film starring deaf actress Marlee Matlin. It sucked. The whole focus of the film is on speech and the "love story" aspect is revolting, although it's fun watching her sign.

"BREAKING THE WAVES" 1997 film about a man who becomes paralyzed shortly after marriage and forces his wife to take other lovers. I actually thought this 2½ hour movie was going somewhere until it's horrible ending when I realized the director was an idiot. One day he's paralyzed and three days later he's walking on crutches. It's physically impossible!

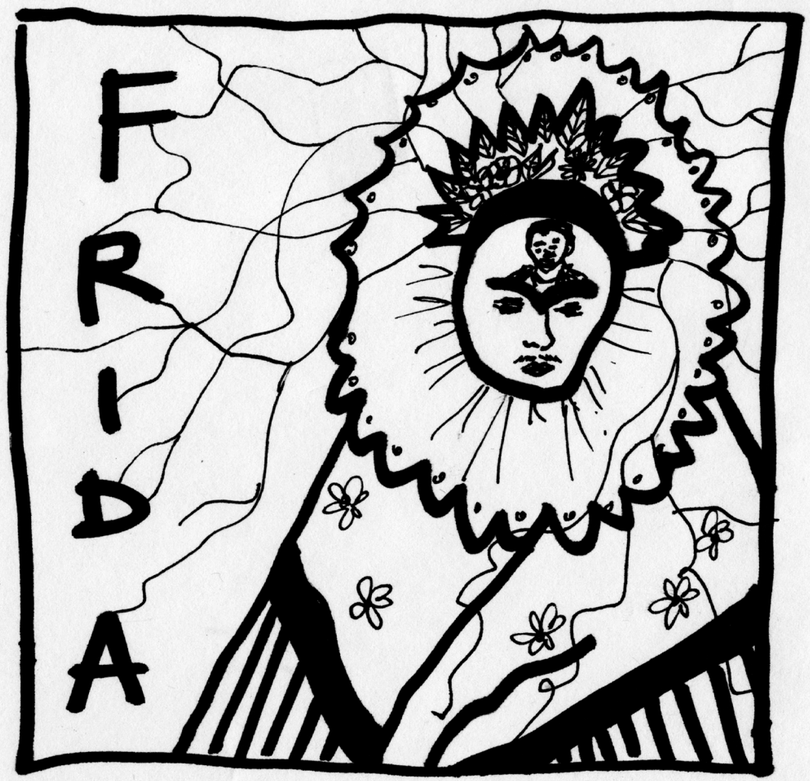
"MY LEFT FOOT" 1989 film about Christy Brown, an Irish boy with cerebral palsy who grows up to become an author and artist. This movie was by far the best of the three. Apparently it's based on a book which I'd like to find. (73)


"BAD-NESS" 8/98
I visited San Francisco and took the BART Downtown and rode to the museum on a bike all by myself.
I'd been really nervous about taking the bike. But it was actually easier than walking. Plus, it was way more empowering than crutches, which is what I normally would have taken.
I Got A LOT of encouragement from people on the street...
hey sister. you are beautiful. you're doing great. (pat hand on heart)
keep up the good work! you are a pretty girl. y'know, my daughter is handicapped, too...
I saw you in the Mission the other day and I wanted to give you a flower...
LEGALIZE IT
74


All was good: I'd conquered my fear of taking on an unknown city alone.
Then I got to the BART station.
the cop told me I couldn't take a bike on BART between 4:30 and 6:30PM. But I had to meet a friend. I didn't know what to do. He wouldn't let me on. He said you should have planned ahead. I said I hadn't known. He said I'd have to ride to where I was going.
NO.
all of a sudden I had no control.
I freaked out & cried in the hallway till I collected myself.
WHY WAS IT SO SCARY
CIVIC CENTER
the smallest obstacle made me feel helpless.
5:12PM
RESULT: I rode the twenty blocks & met my friend. It wasn't so bad after all. But now I knew how vulnerable I felt in the city without a car.
75


"Prego"
IT'S IN THERE!
It's a funny thing having a PREG-NANT roommate... the three of us just got a house and she got nicnamed Prego. And let me tell you-- between her and me, get-ting the house repairs done is no easy task!!
Q: Why?
PUR
pa in!
A: She can't bend over cuz of her tummy, and I can't stand up for too long cuz my legs'll hurt.
...ZZZ...
she's always sleepin' and I'm always sittin, And our Able-bodied roommate works full-time.
...Housework goes slow...
76


TRAVELLERS always have a great time at our place. And the ABLE-BODIED ones are always volun-teering to lend a hand!
oh my, god, the pain!
bags of CRAP from the former junkie tennants
YAH! and when you're done dumpin' those, there's more in the BASE-MENT! OR ELSE!
ONE SIMILARITY I'VE NOTICED IS...
we both tend to stick our BUTTS out a LOT. Prego's tummy forces her to balance her weight differently And for some reason (only the Goddess knows why) having FAKE LEGS makes my butt pooch out when I walk and when I stand up...
★WHOOMP★ DERE IT IS!!
THE END
AUG 1998
77



+ ME.

On the first year anniversary of my tram accident I read through Frida Kahlo's diary and a book of letters she'd sent during her lifetime. On that day I first wrote in my journal how I felt about my connection with Frida, a flamboyant Mexican painter who died in 1954. Unfortunately the journal I wrote that story in got lost, so now I'm writing it again - Dec 1998.

I've loved Frida's work since I was fifteen. I had one book of her paintings that I would read through over + over, always noticing something different I'd never seen before. Her paintings were so incredibly intricate, with so many layers to them that it often took me many long

moments of staring before I totally caught on to her meaning.

I remember about one month before my tram accident I was in San Francisco for the Dirty Bird queerpunk fest and there happened to be a Frida Kahlo/Diego Rivera exhibit showing at the SF MoMA. I went alone and spent two hours staring at about twelve of her paintings, ignoring the 60 or so paintings by Rivera, her husband. "Self Portrait as a Tehuana" ← was the last one I stood looking at. I was surrounded by about 80 billion people but they all disappeared from my mind and I stood with my eyes locked on the painting, staring into her eyes for about twenty minutes, somehow unable to tear myself away.

That was the last time I met w/ Frida before the accident. After that my relationship w/ her changed. On September 14, 1996 I was run over by a train at age 18. On september 17, 1925 Frida was riding a bus that collided with a trolley. My legs were amputated. Her spine, pelvis, collarbone, ribs, and right leg and foot were all broken plus her left shoulder dislocated. she also was 18 and forever afterwards for the rest of her life changed by the fate of her accident. Not only was it traumatic but it disabled her.

I'd always empathised with her pain and suffering, even before my own train wreck. When I would look at her work, especially after having read about her life, I would be deeply affected by the emotion she put into her painting. It was so personal. But I'd never quite known how she felt until I got ran over.

In those first few weeks after my acci-

dent people told me they thought I was Frida kahlo incarnate. Although I knew I wasn't, it was curious to me how much our lives were paralleling all of a sudden. The more I read about Frida, the more I realized: SHE WAS DISABLED! No one had ever actually described her that way before, but that's exactly what she was.

Most of her life was touched by physical pain. Her artwork + writings demonstrated her struggle with pain. Her polio at age seven, accident at eighteen, miscarriages throughout her life and right leg amputation before she died all caused he physical and emotional pain. Watching how she dealt with her pain: sometimes letting it break her down, other times summoning all her will to fight it, was very helpful to me because I had a lot of pain too.



The couple Guillermo Kahlo and Matilde C. de Kahlo give thanks to the virgin for having saved their daughter Frida from the accident that happened in 1925 on the corner of Cuahutemozin and Calzada de Tlalpan

(80)

There are certain heroes I have in life because they never cease to give me constant inspiration on many different levels. Lynda Barry, Leslie Feinberg and Frida kahlo are three people who constantly inspire me. I relate to Frida because of the pain she endured from her relationship with Diego; I understand her for the physical pain she experienced throughout her life, from disability and trauma; I empathise with her ups + downs in mental health; I am totally fucking impressed with the wicked way she played with gender roles in the early century: chopping off her hair and wearing men's suits (stunning); her costumes and fancy hairstyles dazzle me; her strong political ideals (albeit different than mine) are impressive; and I strive to keep doing art like she did: in the midst of chaos and from the heart.

In a way I feel like Frida's art helped me prepare for my train accident. The timing of the SF MOMA show returned her to the forefront of my mind right before I got run over. Also, another artist by the name of Matuschka had struck me, too. Matuschka was a breast cancer survivor who did art surrounding breast cancer and her mastectomy. Why I was so obsessed with radical mastectomy imagery + Frida's paintings I could not figure out, but now, after the accident, I wonder if they were preparing me for the loss of my legs. Definitely after the accident I find myself looking at both of their pictures a lot.

(81)

Frida's legacy of writing and art is constantly inspiring to me. I am forever drawn to her.

HH

CATHOLIC?

Olympia area dyke seeks dedicated sponsor for catholic confirmation. You must be female and confirmed and happily practicing, and OK with Gays. God wants you to sponsor me. ☎ 6715

...OR NOT TO WANK

sometimes masturbation is not a good idea. I know it seems out of character for me to say that, but it's true. Most of the time jerking off is FAN-TASTIC and vital, but sometimes wanking leaves me feeling really shitty. Not because of dirty guilt for touching myself but for a lot of other reasons such as:

BLEEDING, When I'm on my period jerking off does not feel terribly great. My cunt gets ache-y and tender and sticking just about anything in it makes it feel bad, including dildoes, fingers, electric toothbrush holders, even running water from the bathtub. when it shoots into my cunt and fills it, I'm so busy aching I can barely appreciate that I'm cumming.

A SORE CLIT. It's a fact of life that wanking yrself a whole lot on a regular basis (which I do) can cause yr clit to HURT !!!!!!



or yr cock, asshole, pussy, nipples, whatever... YOU HAVE TO BE CAREFUL !!! Sometimes I get so tense or bored or freaked out that even though I know it'll hurt I'll jerk off for the fifteenth time that week anyway. Sometimes the pain adds to it and is good, but other times it really doesn't even feel good at all and I end up getting out of the bathtub wondering, "Why did I do that?" It can be such a mindfuck. - Jerking off to make myself feel better and it ends up making me feel worse. It can be fucking frustrating.

FANTASY MATERIAL. Yr unrequitted crush is painful and tiring. You can't get over them because they're so hot, and you can't stop jerking off to pervy images of them either. Now, I am all for jerking off to the thoughts and fantasies of whatever the fuck you want. Fantasies are fabulous. But painful crushes are painful because they hurt yr heart. And fantasizing about someone you want who doesn't want you can be SO DEPRESSING!! Definitely not always, but it's important to know when not to just stick my cunt under the bathtub faucet. I think it has a lot to do with safety and protecting my sanity. I have a little bathing ritual where I sit in front of a mirror with my legs spread b-4 I get in the tub and just kind of check in with my cunt. Today when I did that I couldn't help but feel deformed. My tits, shriveled legs and everything just made me feel like a freak. At times like those I know to just put my binder back on and leave the bathroom.

HH 4/98

COPY, CLIP + SAVE for that someone special →

BIG JOHN

IF I TOLD YOU YOU HAD A NICE BODY

(WOULD YOU HOLD IT AGAINST ME?)



AIMEE

"I want to stress that I didn't need these legs to feel complete, because I felt that before," she says. "One reason I want to model is to do projects that challenge people's idea of beauty and the myth that disabled people are less capable, less interesting. That we're asexual. I want to expose people to disability as something that they can't pity or fear or closet, but something that they accept and maybe want to emulate. To me, beauty is when people radiate that they like themselves." — AIMEE MULLINS, from an article on her in Womensport magazine.

Did you know that there is an amputee poster girl popular in the media right now? Maybe you think it's me, but it's not. It's some other blonde chick named Aimee Mullins, and she 's 23, from the East Coast and has bilateral below-knee leg amputations. Lately she's been in about six magazines so far, sometimes on the cover, and has been on several television shows including Rosie O' Donnell. It seems like the media was ready for an attractive young crip to promote. So, what do I think of her?

(86)

MULLINS

Well, about a year and a half ago my dad came home with a magazine from the doctor's office that had an article about this girl Aimee in it. The article was all about how Aimee had taught herself how to run and had become an amputee track star. I got really into the article because Aimee was my age, had almost the same legs as me, and was totally kick-ass. Not only did she teach herself how to run, but she got a coach, started competing, went to the Paralympics, ran against athletes only missing one leg, and now she's learning how to do the high jump. Plus she's young, foxy and smart.

I was so inspired that I learned how to run, too. Learning how to run was a totally big deal and Aimee was the one who gave me the idea.

I'm glad that Aimee is so popular in the media right now because she is articulate and motivated and seems like a really great person. She has some good things to say about disability and is a pretty rocking example of a kick-ass crip. I think she wants more than to just get herself famous. I think she goes public out of a feeling of responsibility she has to do something positive for all disabled people.

But I'm not sure how I feel about her being <u>the only</u> disability poster girl in the mass media. First of all, she's thin, blonde, young, straight and upper-middle class: not much different than your normal covergirl except this time the legs are fake. She's a pretty safe crip to have on the cover of a magazine because she 's pretty and her disability isn't so hideous that it'll gross people out (like thank God she's not in a wheelchair, that would just be depressing! And besides wheelchairs are yucky! ...I hope you know I'm joking...). However, I <u>do</u> like what she has to say: she wants all amputees to have adequate health care and nice legs. She also wants to break down stereotypes about disability and show that crips are powerful and we can do whatever we want. And I have to admit that seeing her in pictures is pretty fun - a lot of the time she's wearing a mini dress or tight pants because she's also a model in addition to being an athlete, and it's exciting to see a glamorous crip, but I like the pictures of her running track a lot better. Although it's not like we have many disabled idols to choose from.

But what are some things I wish? I wish that in pictures of her in magazines she would pose <u>without</u> her artificial legs on. Aimee has the lucky fortune to own about five different pairs of legs: she has running legs, walking legs, cosmetic legs, swimming legs, and artsy designer runway legs, so all this emphasis goes on her fake leg collection and how nice it is that she can pass as an able-bodied girl with her nice legs. Well, this is unsettling for two reasons. First of all, most amputees don't have the money to get the legs she has, and I know she knows that and speaks about how in a "perfect world" all amputees could have beautiful artificial legs, but the reality is that most people will never get that. It makes her a little less inspiring because she is hard for most amputees to relate to. Second of all, the emphasis on her artificial legs almost glorifies how she can pass as able-bodied instead of emphasizing the beauty of her real legs. Since a lot of what she speaks about in her articles is how society needs to redefine the concept of beauty, I wish that she would make more of an effort to show the public what an amputee's flesh and blood legs look like, because that is truly a taboo that needs to be broken down.

HH 3/99

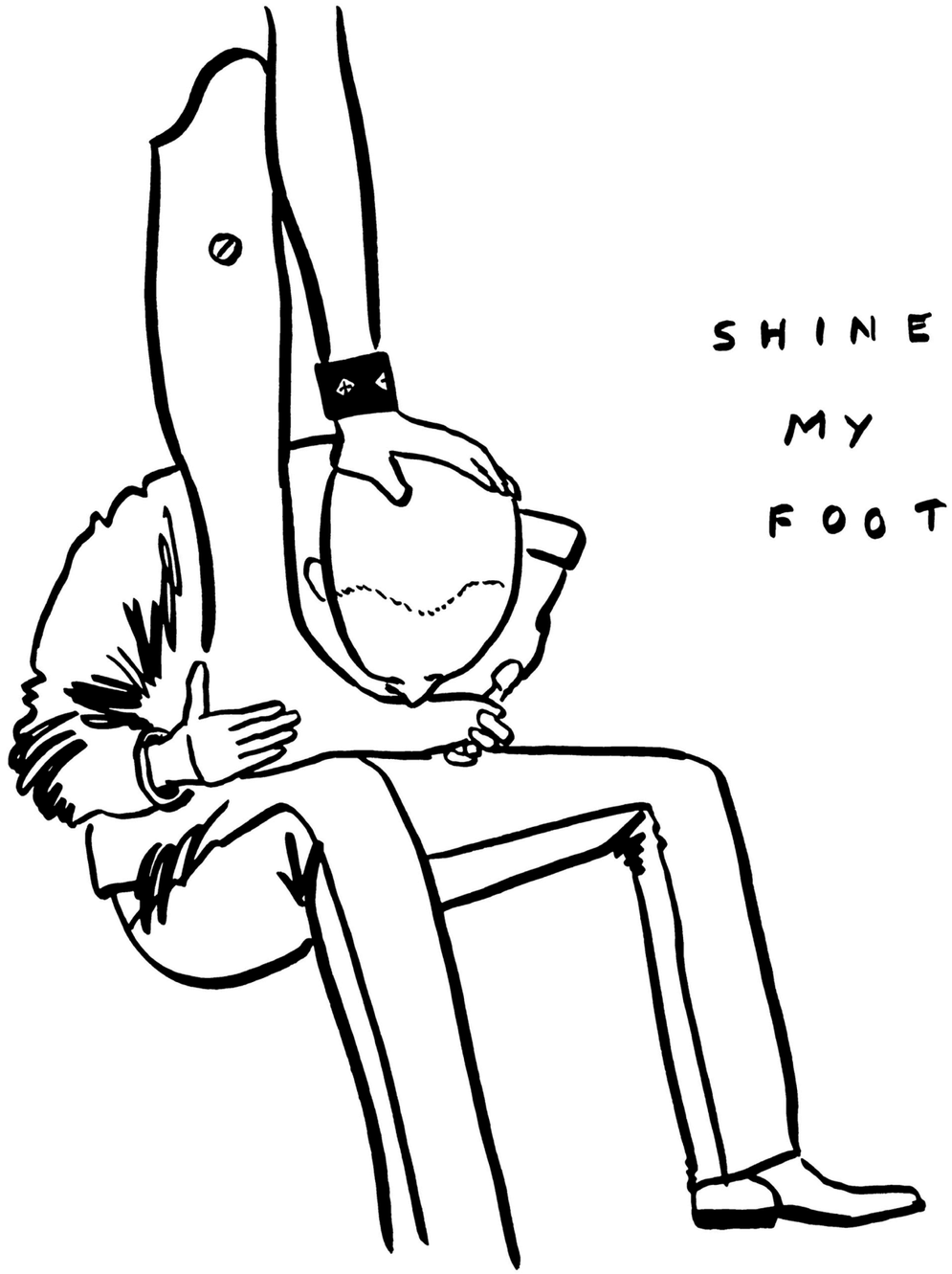
(87)


THE ADVENTURES OF Prego AND PEGLEG
"Ralph's thriftway"
PREGO
PEGLEG
We set off for a night's marauding. This particular evening we had a special mission. Wreak mayhem at RALPH'S THRIFTWAY (and buy some groceries...)
evil spawn
We imported an accomplice from the northern territory: the evil MASS-SCARAH. we rallied together our powers and headed off towards destruction in my 1986 subaru station wagon a.k.a. the...
CRIPMOBILE
88


In the parking lot we encountered hostility before we even exited THE CRIPMOBILE. An evil man in the next spot told me not ONCE, but TWICE that I was in the WRONG parking space. Well, I informed him that I, THE KILLER PEGLEG WAS handicapped! And with that said, PREGO and MASS-SCARAH vaporized him, AND his truck!
the fucker thought I was too young to be a CRIP. He learned his LESSON...
MASS-SCARAH
THAT SPACE IS FOR THE HANDI-CAPPED! ...AHHH!!!
WE ENTERED the THRIFTWAY
Prego had reached her fifth month of pregnancy and how we could both use the motorized carts! t'was an evening for celebration. the able- and full-bodied MASS-SCARAH accompanied us on our journey 'round the store while the management waved on, happy to oblige their disabled customers... unaware that, in fact, we were up to NO GOOD.
ALPH'S
89


We were rippin up the aisles, goin round and round in circles. Prego cackled maniacly as she mastered control of her cart. Although it was her first time she quickly gained confidence and immediately started showing off with some tricks...
HEY! LOOK AT ME!!!
APPLES
SHE FOUND OUT SHE COULD SWIVEL + DRIVE SIDEWAYS! IT WAS ALL FUN + GAMES, UNTIL...
90


WHOA!!
7/99
She had a head-on collision with a large rack of hanging kitchen utensils. Stricken with fear her hand was frozen on the controls. Unable to stop herself she screamed for help. Heroically MASS-SCARAH saved the day and steadied the rack. This minor brush with destruction was only the beginning of the evening of terrorism that lay ahead...
MH
91



SHINE
MY
FOOT

PAIN POETRY

Walking I get an endorphin rush from the pain that comes
There's a sigh of resolution when I put my legs on in the morning
There's a sigh of relief when I take them off at night
It smarted when she smacked my arm
And my skin flushed red there
It felt good

Rate your pain on a scale of 0 to 10
Is what I say at work
It gives me an idea of where you're coming from
One person's 2 is another person's 8
But how will I ever know anyway
One lady came to see me for her hip
But talked more about her dead husband
I've never really experienced pain before now she said

The boiling water flush
The hot wax ripped off
The bite on my neck
And the release that seals me

Which pain is the worst
Is it the dreams I can't escape
Or the times when I don't know myself
The cysts that keep me off my feet
Or the punishing embarassment of making a mistake

It is a wound and a gift
A trial and a peace
To avoid it is to run forever
To relinquish to it can be the greatest joy

2007

GROWING A NEW LENS

A SERIES OF ESSAYS ON INNOVATIVE ARTISTS

For years I have been collecting an ongoing list of artists who acquired a disability or chronic illness, and instead of it ruining their art career, the change in their health became a catalyst for their creative work to evolve in exciting ways. I seek out the stories of innovative artists because I am an artist, and I have seen how disability, PTSD and chronic pain have been a challenge to my creative process, but have also added immeasurable richness to the work that I create. Because there can be hardship associated with the ongoing stress of a medical condition or the acquisition of a disability many people do not see how these experiences can be extremely fruitful for the development of a new lens, a way of viewing the world that has the power to reframe our story in unexpected ways.

CHALLENGING THE NOTION OF INSPIRATION

How do I write about people whose work I draw from without falling into the trappings of "inspiration porn?" Inspiration porn is a term coined in disability culture to expose the tokenizing phenomenon of labeling disabled people "inspirational" for simple things like being happy or leaving the house. I will give an example. There was a high school student in 2013 who made national news because he scored a touchdown in a school football game. The reason this made national news was because the student has Down Syndrome. While many people felt this story was inspirational I found it patronizing. What high school student makes national news for making a touchdown? The high school newspaper maybe, but not the national news. I think the reason the public found this event exceptional was because the public has a lower set of expectations for people with any kind of disability. When we demonstrate our talent or competence it is seen as miraculous. This kind of appreciation, instead of feeling supportive and encouraging, feels patronizing.

On the other hand, disability advocates have become so aggravated by the trite use of the word inspirational to describe us, that I wonder to myself, When is it ok to feel inspired by other people with disabilities? How do I do that without falling into the trap of being inspired for the wrong reasons? Inspiration can be tokenizing, but it can also be honoring, depending on how it is done. There is a double leg amputee, Amy Purdy, on Dancing With the Stars right now. The entire nation is watching her dance on television, and going wild over her. My feelings about the media coverage are mixed. On the one hand she does dance really well, so props to her! On the other hand, as a double leg amputee, I know that certain dance moves are actually not that hard. So, I was impressed, but it did not blow my mind, like it did for most people who assume that someone with artificial legs can't dance at all.

OUTSIDER ART

For those of you who don't know, there is a whole genre of art titled "outsider art." This genre focuses on artists who are not formally trained and considers their work to be original and authentic, untainted by the influence of the mainstream art world. When it was first invented in 1972, outsider art featured people

who were on the margins of the art world, usually asylum residents and children. Eventually the genre was expanded to include other categories of artists including former slaves, people of color, poor folks, and people living in remote areas. In other words, anyone who could be considered part of a minority group or live without knowledge of mainstream culture. This aspect of this genre is very off-putting to me. The exotification of these artists' work minimizes the fresh perspective they bring to their creations. Although there is a small group of artists who choose to label themselves as outsider artists in protest to the commercialized art world, most of the artists labeled "outsider" have been done so by art critics.

I recently saw *Marwencol*, a documentary about photographer and diorama artist Mark Hogancamp, who was attacked in 2000 and acquired a severe brain injury. Even though through rehabilitation he learned how to walk and talk again the brain injury caused memory loss, and Mark lost all memory of his life before the attack. As art therapy Mark created a diorama-sized world called Marwencol. It has human figures in it and he plays out different scenes with the characters, many of them patterned after people he knows in real life. Then, he photographs the scenes. Not only is this his creative expression, but because he cannot afford counseling, it is also healing for him. Halfway through the documentary it was revealed that Mark is a crossdresser and owns over two hundred pairs of women's shoes. Of course, I cried when the film revealed he was attacked because some guys at the bar found out he is a crossdresser. There is a touching scene where Mark's friend describes how Mark came home from the hospital after the attack and asked: "Why do I have so many pairs of women's shoes? Do I have a girlfriend?" The friend replied, "Mark those shoes are yours."

I read an article that labeled Mark's work as outsider art. It didn't sit right with me. I thought to myself, Why is it outsider art and not just art? Is it because he has a brain injury? I think his art gives us a window into his unusual mind. But, we all have unusual minds. Is it because his creations are art therapy? Many artists find healing from making what they make. And this idea of him as an outsider artist is complicated by the fact that his art is so well received that he now exhibits and sells his work in galleries. If Mark chooses to call his work outsider art that is one thing, but for a critic to call him an outsider artist, that's another.

THE IMPACT MONEY HAS

Some of the artists I chose to write about in "Growing a New Lens" like Yayoi Kusama, Chuck Close, and Rick Allen had already achieved massive commercial success from their art career when their health needs increased, so money was not a barrier for them. If only all disabled artists were so fortunate. Dancer Homer Avila developed a rare form of cancer that went undetected for a long time because he could not afford health insurance. A fund for artists was formed to assist him and others who could not pay their catastrophic medical bills. Many non-disabled artists I know are able to live an artist lifestyle, getting by on little money, because they have few healthcare, dietary, transportation or housing needs.

STAYING ALIVE

As people with disabilities, we are constantly having to prove our right to exist. Pre-emptive abortion and genetic counseling are fancy terms for eugenics. Disabled people are frequently portrayed as non-human, less than human or magical creatures who are other than human. The title of the disability rights documentary *Lives Worth Living* is a reminder to the general public of just that: disabled people's lives are worth living. I think a lot about the Not Dead Yet (NDY) movement. NDY is an activist group largely made of people with disabilities and chronic illness who challenge the notion that life is not worth living if you have a serious

health condition or difference. NDY question the ulterior motives of the movement for euthanasia, otherwise known as assisted suicide, by pointing out the negative implications of euthanasia, namely eugenics (eliminating members of society who are not considered "desirable"), financial benefits and internalized ableism.

I learned recently that the artist Lisa Bufano took her own life toward the end of 2013. Lisa was a performance artist and dancer who collaborated with AXIS dance company in California, as well as Homer Avila, one of the artists featured in this essay series. Friends told me about Lisa; when you are an amputee people love to tell you about cool amputees they know about. She was close to my age and had a similar performance aesthetic. I like how she explored the range of movement that was unique to her body. There is a video of her swimming underwater with an enormous black mermaid-like fin attached to the ends of her legs. As someone who doesn't like swimming near children because I don't like being stared at for my difference, her movements evoke feelings deep and raw. Her choices felt unexpected. She was not afraid to redefine her body on stage in ways that were ugly, or challenging. I always respect people who are able to show their quote unquote deformities in their art in ways that do not exoticize their body, play into expectations about disabled art, or try to conform to non-disabled prescriptions. So, I hate to hear that she took her own life. There is a part of me that wants to trust that she did what was right for her, but as me, as someone who is still alive, it is also really painful for me to think about that.

It is because of people like Lisa that I must write "Growing a New Lens." That I must write at all. I want to celebrate the artists who chose to live. I want to have role models who lived. And who never stopped making art.

HOMER AVILA
(1955-2004)

Modern dance may not be for everyone. Like my parents, for instance, they don't really get it. But, I like modern dance. Well, I should say I like good modern dance. The kind that gets me out of my head and even if I don't know what it meant, I liked that it was unexpected. When I was thinking about what artists I wanted to write about for this biographical essay series "Growing a New Lens." Homer Avila was one of the first people I thought about because, simply, I love watching him dance. I discovered his legacy of work years after he died through videos of his performances. Passed on in 2004, Homer was a professional dancer who lost his right leg at the hip due to cancer. His grace, precision and professional background prepared him well to explore dance with three limbs. Embracing his situation for what it was (Homer died of cancer three years after his diagnosis) he not only kept dancing, but he innovated new ways of moving.

MEETING HOMER

My introduction to Homer was at a Society for Disability Studies conference where a short film about him, *Phoenix Dance*, was screened. The film chronicles a duet choreographed for Homer and dancer Andreas Flores by Alonzo King, titled *Pas*. This film was nominated for an Academy Award in the category of Best Documentary Short. Like *Murderball*, which lost for Best Documentary Feature to *March of the Penguins*, it did not win. (For some reason the Oscar always goes to nondisabled actors who portray us, but never to authentic portrayals of us living our own lives). In *Phoenix Dance* I was struck with how he moved with his partner. Standing alone he balanced precariously, just so, on his one leg. In the dance she and him experimented with trust, with balance that was momentary, precious. She leaned into him in a counterbalance, and he with her. Lean in. Then, lean in some more. Start moving together. Tentatively at first, until… gasp! He played with the audience's fear that he might fall on his face. And when he did fall down the audience held their breath. Was that an accident? Only to witness him roll effortlessly into a dance on the floor, spring up on one leg and leap in the air.

It's dance like this that teaches us deep lessons about life, yet in no words whatsoever. I felt a wry smile cross my face reflexively. He's fucking with them, I thought.

BODY OF WORK

Homer was a dancer for many years. His family came from El Salvador, he grew up in New Orleans, and in 1976, at age 21 he arrived in New York with no money, no family support, a limited education, few friends and a bunch of dance scholarships. He trained with many dance greats such as Twyla Tharp, and established himself as a professional dancer. Eventually with Edisa Weeks, he co-founded Avila/Weeks Dance in 1991, and they performed together internationally until 2001, when, after his diagnosis, he began performing as a solo dancer. After 2001 he continued to train, choreograph, and perform at venues across the world, including the Kennedy Center/Millenium Stage, The Guggenheim Museum, and Ballet Frankfurt. Respected choreographers were stimulated by the opportunity Homer offered them - a professionally trained dancer who had experienced a dramatic change of his physical being and spiritual self. No better offering for their creative powers. The weekend he died in 2004, he performed on a Friday, checked himself into the hospital Saturday, and died the day after that. In essence he danced right up to the hospital door.

STAGING BROKEN DANCE

I knew I needed to write about Homer. His work is so easy for me to watch, and I kept coming back to it. I think it is because of the emotional quality of his dance. Simple movements of his are given great attention and feeling. He is able to demonstrate tensile strength and precarious fragility simultaneously. He contrasts beautiful movements with challenging ones. He's not trying to make this pretty for us. He'll do moves like leaping on one leg, and turning and spinning with precision, movements that bely his many years of skilled training and acute attention to the capabilities of the body. Then, he'll crawl across the floor on hands and knee, or scoot on his ass across the stage. Movements I relate to. Things we never see on television or in the movies. I love how he brings that to the stage. Staging a broken body. He exacts his skill, and his astute level of physical embodiment to redefine broken. There's a sense of acceptance and also of loss. He is able to bring all of those feelings to the dance, simultaneously.

How many disabled people fall down every day, while walking, while transferring in and out of their wheelchairs? So many that Medicare requires all clinicians to ask the question, "Have you fallen in the last three months?" Homer danced that. He danced falling down. He danced crawling on the ground. I've crawled through dirt more times than I care to admit because the way wasn't accessible. He danced his own version of that. The dance is a release, and a reclamation.

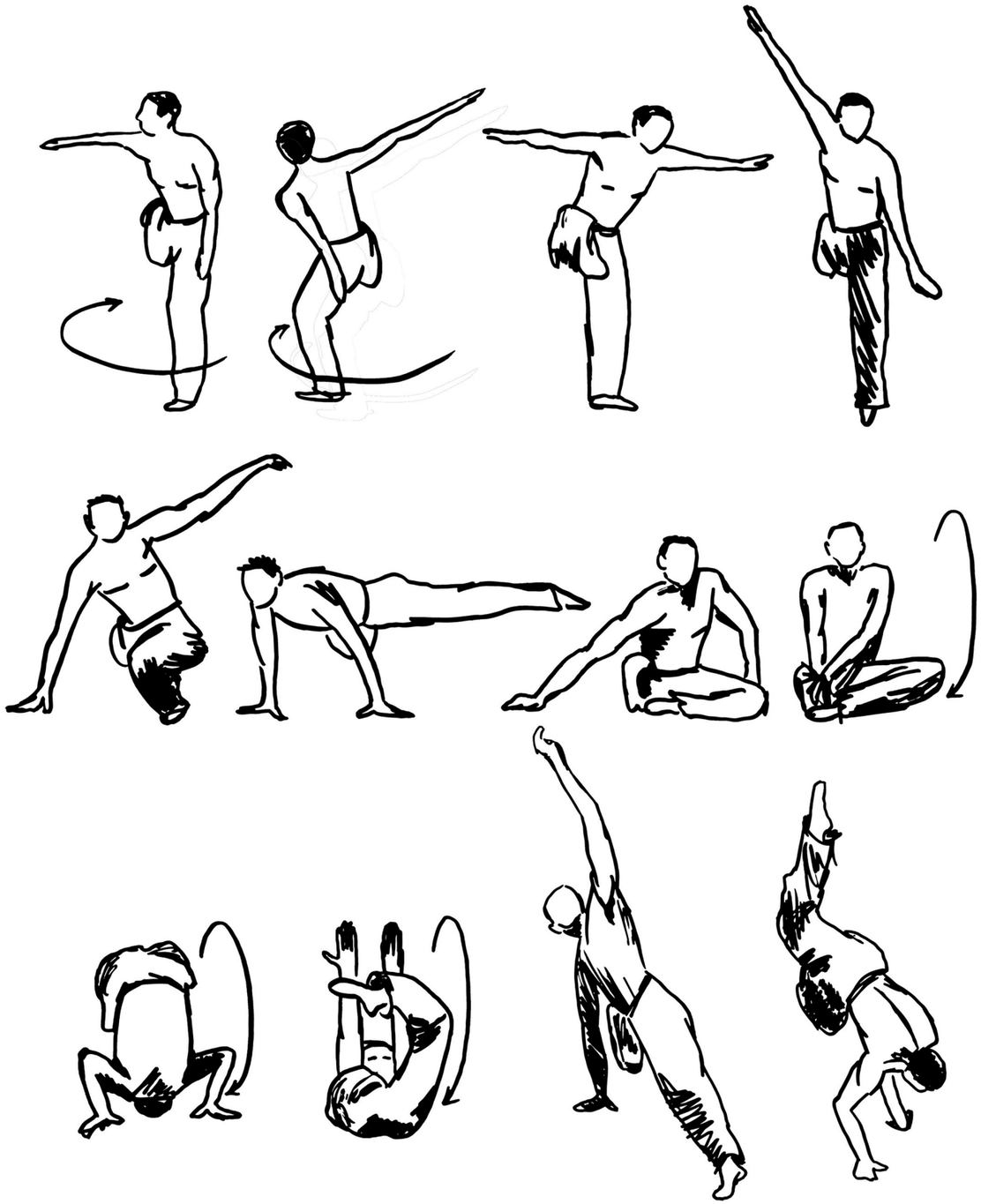
Once I watched a non-disabled dancer perform a dance where she sat on the floor and picked up each leg, one at a time, with her hands, moving them as if they were limp. In this manner she moved across the stage. Later, I got into my truck to go home and I picked up each leg and put it in the truck because that's what I do when I get in. My friend said, "She stole that move from disabled people." I thought, *Yah she did!* And, then I thought, *But don't we all steal moves? Aren't we all inspired by things we see other people doing?* I don't think most people have thought a lot about the appropriation of disability culture. I think that is because most people don't even realize such a thing as disability culture exists.

My aunt Maren died of cancer a few years ago. She had been a dancer all her life. A few years before she died she performed in a duet with a dancer half her age. Even though the piece itself was about aging and the different stages of life, I remember Maren telling me she felt self-conscious about how the tremor in her hands was noticeable during the piece. I marveled that all the years Maren and I had talked about integrated dance it still hadn't sunk in that she could be a great dancer with a tremor.

INTEGRATED DANCE

In the last three years of his career the reach of Homer's work grew tremendously. Homer also embraced disability community in his last three years performing as a guest dancer with AXIS dance, and at disability conferences. It was at one of these conferences that he met Simi Linton, author of *Claiming Disability*. I gained a more intimate understanding of Homer through Simi's chapter "Odyssey of a Sure-Footed Man" from her memoir *My Body Politic*. Her telling of the intimate friendship she formed with Homer during the last years of his life explores their connection, and documents the incredible person Homer was, in a very personal way. When the work of an artist touches us, a relationship forms. An intimate understanding is created within oneself in reaction to the work. In that way I have my own relationship to Homer's work.

Many audiences have their minds blown from seeing a disabled dancer do something really impressive because our bodies are not often thought of as impressive. Our culture still does not know what to do with a disabled person. Most people are socially awkward around anyone with a noticeable disability. Few people have what author Eli Clare calls crip comfort, social comfort with disabled people and the disability experience. Integrated dance is a way of exploring how different bodies can move together,



how people from different cultures can move together. Integrated dance actively creates culture. In some ways integrated dance has the power to show audiences (and the dancers, too) what living together can look like, feel like, sound like. There are many integrated dance troupes out there, featuring a combination of disabled and non-disabled dancers, who are doing great work. Some examples from the United States are Dance>Detour in Chicago, Light Motion in Seattle, and AXIS dance out of California's Bay Area.

TAKING INNOVATIVE DANCE SERIOUSLY

As much as I enjoy integrated dance, there is a part of me, the proud part of me, that wonders why we need non-disabled dancers on the stage with us. Sometimes onstage, when disabled and non-disabled dancers are performing together, it feels like the focus is still on the non-disabled dancers. That they are there to lend credibility to the dance. To add polish, or beauty, or skill. Part of me resents that.

All disabled people are inventors of movements never created before. Onstage or off.

Sometimes it feels like integrated performance is still centered in the idea that beautiful movements are the only ones worth watching. In this way it doesn't feel like a new model of dance is being created, instead that the old ideas of what is "good" dance are being reinforced. In an ableist world that forces disabled people to fit into non-disabled expectations, it feels so much more exciting to watch dance that bends expectations to ones that are bigger and more interesting. I want to see more dance where sick and disabled dancers move with each other. In disability community there is the concept of collective access, the idea that sick and disabled people can collaborate with each other to accomplish tasks and meet each other's access needs. Dance is a powerful way that we can perform those concepts.

There are some great examples of dancers doing this type of work in Portland, Oregon. Wobbly Dance, Impetus Arts, and the Disability Pride Arts and Culture Project. Antoine Hunter is an incredible Bay Area dancer. He is also Deaf, and organizes the Bay Area Deaf Dance Festival. Hourth, otherwise known as Jean Sok, and Lazy Legs are two dancers I love to watch. Hourth has one leg, like Avila, but instead of doing modern dance Hourth started out in breakdancing and hip-hop, and now he is dancing with Cirque du Soleil. Lazy Legs is a breakdancer on crutches who has both legs, but relies mostly on his arms for walking. There are dance legends like Bill Shannon aka "The Crutch Master." Bill created something I marvel at, a lexicon - essentially a dictionary, of every dance move he ever created for dancing on crutches. It's brilliant to watch. He recorded it on video and systematically demonstrates every dance move and explains its use. It's brilliant and there is no non-disabled equivalent to it. There is nothing that non-disabled dancers do that could be likened to what Bill Shannon has created. In that way Bill has innovated dance. He has brought it to another level.

DEAR HOMER

You left a legacy, and even though you are gone new people keep meeting you through your work.

Thank you so much for the nourishment you have given us.

You will be remembered for many years to come.

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MATTILDA BERNSTEIN SYCAMORE
(1973-

*I met Mattilda in San Francisco in 1996, when friends and I crashed at her place to attend a queer punk festival called Dirty Bird. At that time her hair was turquoise and magenta, her wit was quick and intimidating, and she hadn't been published yet. Eighteen prolific years later her hair is now her natural shade of brown, her wit is still quick, less intimidating, and she has published multiple books including a memoir (*The End of San Francisco*), two novels (*So Many Ways to Sleep Badly *and* Pulling Taffy*), and five anthologies (including* Why Are Faggots So Afraid of Faggots? *and* Nobody Passes*). Knowing Mattilda over a period of time has allowed me to see her develop as an author. Her writing has always been intertwined with her activism. Early in her career she primarily wrote about sex work and being a survivor of sexual abuse. Later anthologies and essays have explored broad themes of passing and assimilation, alternatives to mainstream gay capitalist culture, racism and imperialism, authentic stories by people in sex work and survivors - forming connections across race, class and gender - offerings to build conversations spanning across communities.*

I approached Mattilda to do this essay, which I adapted from an interview because I have seen her writing process and style evolve significantly after she developed chronic pain. Giving up writing was never an option, so she adapted her process – drastically. The pain has affected her work, influenced it, given her new tools to understand and approach her writing.

I recently had a spell of severe tendonitis in both hands and forearms that lasted several weeks. It kept me from doing even the simplest things, like brushing my teeth and washing my hair. Even though I regained my ability to use my arms without pain, for close to a month it was unclear if that would happen. Unable to write or draw during that time, I thought a lot about Mattilda, how she could not let pain stop her, and how she adapted her writing practice in order to continue her life as a writer.

Mattilda spends most of her days in her apartment. She has the classic home of an author. Her walls are covered in rows of bookshelves that reach to the ceiling. There are big picture windows that let in natural light, a precious resource in Seattle. She has her writing desk set up with plants surrounding it, abundant with foliage. Most of the art hanging on her walls are framed paintings and collages made by her grandmother, who was a visual artist. We talked in her apartment one night about how she views her writing process now, how she has changed, and how her writing process has changed with her. Knowing that I've been experimenting with different interview styles to make the transcription process less labor intensive, she spoke succinctly, knowing that I was typing her words as she spoke.

The following text is Mattilda speaking in her own words from the interview we did in 2013 at her home in Seattle, Washington.

WRITING

I write in order to stay alive. I write because it's the way that I can understand myself and express all the contradictions, hope, tragedy. It's how I think. I've been writing so long. It's how I engage with the world. It's how I find my place in the world. It's one way I'm not able to feel hopeless all the time. Because, I feel hopeless a lot. I'm able to write about it, which makes me feel less hopeless. And, it's my creative expression. People I may not know choose to connect with it. I search for connection or possibility. So, in a way, I write to not give up. Also, things that mean something to me, do not exist generally in the world, especially in media. Representations of faggotry, sexual splendor, flamboyance, gender transgression, public sex, sex work, talking about sexual abuse and activism, the way these things are portrayed in the media are

oversimplified, and overexplicated, and meaningless, and useless, and so far from the actual experiences that are supposedly contained within. I'm interested in authentic representations that are intimate, nuanced, expressive and challenging.

THE WRITING PROCESS

My writing practice changed pretty dramatically when I first became aware of chronic pain and when it became debilitating. What I'd always done in the past was I didn't write that often. If something happened to me I needed to write it down or it would disappear, or I would disappear. As someone who was sexually abused as a kid documenting my story was really important. If I don't get this story written now, it's gone. When I first developed chronic pain it began in my wrists, arms, hands and fingers, so I couldn't do the kind of writing where I'm so frantic, and I type it all out in a few hours. At first I was really overwhelmed. Writing has always been the one thing I have access to on a regular basis as a way to express myself and process the world and intervene.

... I made a choice to make my writing more vulnerable in order to connect to people, rather than invulnerability, which I had previously chosen in order to connect to people.

When I was writing *So Many Ways to Sleep Badly*, my second novel, I attempted to use voice activated software. When I started version three of Dragon NaturallySpeaking there were some challenges. I would dictate, "I'm walking down Polk street." and it might write, "burn down the White House." or "clothing sale dominant extra indicate." It made it hard to go back and know what I meant by that. I was training the software. It took me a year. Basically, it was useless. I also tried a period of having a friend transcribe, but that was difficult. Now it's version twelve. Every version has a lot of glitches, though. Sometimes when I'm writing it crashes. It takes a lot of computer resources to use it. There are certain things it will never learn, like the word fuck, for example, is always fark. Or, shit will always be ship. "What the fark was I saying there?" Using voice activated software changes the way you write. When you type or write by hand the physical act is part of the thought process and vice versa. Even the act of speaking is different than the physical act of writing by hand or typing. So, it takes a long time for those two to come together. I think what's exciting for me, once it became engrained, I could kind of speak like I'm writing.

BEING AN EXPERIMENTAL WRITER

Luckily, I see myself as an experimental writer. I don't believe in conventional plot structure. I thought, well usually I always write without any intention of narrative. I thought, what if I took this further and wrote two paragraphs a day. I would have no intention of plot whatsoever and just write what came into my head. It condensed my writing process, but made it daily. It made me really aware. As I started writing it made me aware of the things I was writing about: my apartment, chronic pain, bad sex, incest memories, conversations on the phone, conversations in person, friendships, sex for pay and sex for play and what was the difference. I wrote about NPR because it was on the radio in my house, I wrote about Whole Foods, I wrote about activism, because that was my life. I wrote about music, I wrote about street life, street culture. I wrote about the bus. I wrote about relationships. I had this boyfriend, but I didn't know that when I first started writing about him. I wrote about decay, rape, and pigeons in my apartment. I wrote about the crumbling of my own body, the war in Iraq that started in 2004. I wrote about impending war. But, everything was really condensed. Something that would have been a whole story before, was now a sentence.



I wrote three or four hundred pages in a few years. I looked at it and was so excited. There's actually something that emerges! The repetition of theme and tone and texture and sound and voice is what drives the narrative. The things I was interested in became the structure. I didn't have an intention of here's what I want to happen and when, and that worked.

MAKING WRITING MORE VULNERABLE

I confronted my father about sexually abusing me in 1995, and in 2006 he was dying of terminal cancer. I made the decision to visit him before he died even though he had not acknowledged anything. I wanted no regrets. Also, I wanted him to acknowledge the past.

It would change my life. I went back to the house where I grew up, where I was abused, and hadn't been in fifteen years. At that point I wanted my writing to be more vulnerable. In order to survive as a queer kid and an abuse survivor I had to project invulnerability. Deciding to visit my father, I made a choice to make my writing more vulnerable in order to connect to people, rather than invulnerability, which I had previously chosen in order to connect to people. I was able to go to the place where I grew up and be vulnerable in a space that was not safe for me. I told my father that I loved him, that I didn't want him to die, and that I wish we could have had a relationship.

THE END OF SAN FRANCISCO

I created a blog during that time. After each visit with my father I would go to the blog and write about what I had just done. That writing was different than my typical style, because it was not edited, like usual. I had 1,200 pages of blogs I did all that with voice software. Two hundred of those pages I spent trying to regain hope in my own sexuality. Now that chapter is edited down to fifteen pages. The writing in the blog entries became the raw material for my first memoir, *The End of San Francisco* after I had edited it twelve times (because I'm a neurotic editor).

It ends up being in some ways about San Francisco, about a refuge for radical queer vision, and community building, and in some ways about my formations and their undoing, ethically and emotionally. I moved there when I was nineteen, in 1992. There I formed my own values and ethics; building alternatives to the status quo. It also let me down the most, in so many brutal ways.

I have been writing about all the places where my analysis has failed me (and people, places, cultures – everything I thought was an alternative to gay and straight normalcy). I still have dreams of accountability, relationships forged through activism, and activism through relationships, the connection of desire to the practice of community. I believe in all those things but they haven't served me other than in having a strong analysis. I'm writing now about things used to work for me, that now make me feel stuck.

WRITING AND PAIN

I think in writing *So Many Ways to Sleep Badly*, I was writing about the chronic pain as it was emerging. I was writing about what started as a crisis and then became engrained in my life. That was thirteen years ago when the chronic pain became debilitating. Now it's part of my identity, in a way. I am still trying to overcome it. It's not just pain now; it's pain, exhaustion, hypersensitivity, migraines, digestive problems, and multiple chemical sensitivities. Each one has its own trajectory and they wind around the other ones in different ways. I've changed my life in many different ways at different times, in order to make it more sustainable with these chronic illnesses.

HOME LIFE

I wouldn't have called it disability, initially. Certainly now I would say that I see myself in that realm. With the radical disability lens I can see things it

has helped me with, in the sense of creating my own space, making my home. Now, within a month of moving in somewhere I set up right way, because I need the house to be a refuge. Ninety percent of the time I'm in my apartment, by myself. Part of that is really nurturing, hopeful, and helpful. I make decisions based on self-knowledge, knowing my limitations. I know I can't carry a bag three blocks without pain. There are some things I love to do, like go dancing, but no way in hell. Largely based on exposure to smoke, in particular – even coming from outside. One thing I've come to learn is that I'm so sensitive to my environment, lighting, air circulation, where I'm sitting. If someone's smoking downstairs it ruins my life. I basically need to live where organic produce, bulk foods, and the bus are all nearby. And also people, trees, and a park where I can walk, not on cement.

GOING ON BOOK TOUR

For me, it's important to tour when I have a new book. That's how I can connect to people I don't know. It helps me feel the impact of my work. Five minutes or twenty seconds of talking to someone really changes how I feel.

I feel overwhelmed almost every day just by struggling to function, by going outside. Yet, I'm hyperfunctional, in a certain way, putting books out. Touring is exhausting. It's exhausting just to take the bus downtown in Seattle. I only tour by train. I can't take planes. Planes will destroy me for four months - headache, physically-induced overwhelming depression. Trains wreck me too, but only for a few days, or a week or two.

When I'm in a new town on tour I need to get groceries immediately. I have to cook all my own food; I'm also vegan. And, I have to have a space for myself, my own room to stay in, otherwise it's too hard for me to tour. I need to be able to shut a door, and feel however I want to feel. If I'm around someone else it takes effort. I focus everything around resting and the book events. I need at least a few days in between events. Sometimes I will stay in a town a few weeks. The only time I travel, really, is when I tour. Sometimes I break up my tours by region, like a Midwest tour, or an East Coast tour.

The events drain me, but the interaction with people gives me energy. I love hugs, not just signing books. It breaks down a barrier as a performer and someone in the audience, now as two people being embodied in the same space. *That* I love.

RICK ALLEN
(1963-

When I was in middle school, Def Leppard, the stadium rock band from England, was at the peak of their popularity. It was the mid 80s and "Pour Some Sugar on Me" was huge. As an adult a couple Def Leppard songs, "Hysteria" and "Animal" became my go-to karaoke jams. It wasn't until years after I became an amputee that I realized Def Leppard has a one-armed drummer, Rick Allen.

I did not include Rick Allen in this series of essays because I think he is a particularly great guy. Actually, he has been arrested more than once for beating his wife. And even though he founded some non-profits for disabled kids and veterans, the guy is an imperfect role model at best. He is also not the only disabled musician to ever make it big, Ray Charles, Vic Chesnutt, Django Reinhart, and Stevie Wonder are other great examples. But, I chose to write about Rick because I always wanted to know more about his story, because I love metal, because he's an amputee, because it's incredible that a crip drummer made it in such a famous band in an industry so unforgiving, and because his life has not come to a tragic end like some of his peers. Also, I attended Queer Rock Camp last year, and after struggling over how to play a musical instrument my appreciation for how Rick adapted his drum kit really blew my mind.

In 1984 Def Leppard was huge. They had released three albums, two with Rick as the drummer, including their bestselling *Pyromania*, and were one of the biggest rock bands at the time. Rick Allen, nicknamed "Thundergod." joined the band when he was just fifteen. Def Leppard has been called glam metal, heavy metal, and pop metal.

It was on New Years Eve 1984, when Rick was 21, that he was racing another car, lost control of the vehicle and lost his left arm when he was thrown from the car.

KICKING THE FOOT OF THE BED

Rick spent weeks in the hospital after losing his arm. His brother was one of his biggest supporters, and was the one who brought a stereo into Rick's hospital room when Rick was first hurt. At first Rick found it difficult to listen to music; he was afraid he would never be able to play again. Music reminded him of the past, which was too painful at first. His left arm was gone and the right one was broken. He felt totally defeated, like his life as he had known it was over.

The band was very close knit. They were young, still in their early twenties, but had been through a lot, with three full-length albums already released and having shared a lot together. When Rick got hurt the band told him they still wanted him as their drummer and that they would support him through figuring it out, even though none of them had any idea at that time how he would do it.

In the hospital he kept sliding down in his bed, until his feet rested against the footboard. At one point, listening to the stereo, he noticed while in bed that he was able to tap out the beats of the music against the footboard. He kicked the footplates in his wheelchair, too. After listening for a few days, Rick realized he could still play a lot of the drum parts from some favorite songs just using his feet.

There are very few role models for being a person with a disability who is successful at something. Society underestimates us, is so convinced that we can do so very little, that we become convinced of it ourselves.

A friend of mine, dancer and choreographer Charlene Curtiss, of Seattle dance company Light Motion,



shared with me how years after breaking her back in high school, she was sitting somewhere in her wheelchair when some really good music came on. She started moving, her hands and arms and her body, she wasn't thinking about what she was doing, she just moved in response to the music. The music was good. She was feeling it. And she had a revelation. She could still dance. Similarly to Char, with the bare beginnings of an idea, Rick became completely motivated to play drums again, but he had no idea how. He left the hospital, moved in with his parents, and threw himself back into work. He went to Ireland and secluded himself working 8 hours a day, teaching himself how to play drums again. He wanted to be locked away playing where no one could hear him. He didn't want anyone to hear the mistakes he was making during those raw drumming sessions.

HOW HE ADAPTED HIS DRUM KIT

I have never played drums, so I had to learn about drumming to be able to understand what Rick Allen did to adapt his drum kit. He had a friend in electronics that helped him figure out how to adapt the drum pedals. He learned how to use his left foot in place of his left arm, with his right foot playing the bass drum. He set up a series of foot pedal for his hi hat, his kick drum, his snare and his tomtom. He used 3 hi hats. Everything was centered toward the middle of the kit. All the cymbals were centered toward the right side of his kit. He was re-patterning the way his body played music. In the mid 1990s, in order to update his sound, Rick changed his drum set up from the electronic drum sound popular in the 1980s. Instead he used electronic pads to trigger samples made from recordings of his acoustic drums.

He was really nervous to start playing concerts again, especially the huge stadium shows they were used to playing. When he first started back with the band they hired a back up drummer, Jeff Rich, a guy who played for a band called Status Quo, assuming Rick would get tired after a few songs and need someone to finish the set for him. After several concerts, they didn't need the back up drummer anymore. Rick played a few small shows in Ireland before he felt ready to play his first big concert after the accident, the 1986 "Monsters of Rock" festival at Castle Donington in England. The festival was the emotional turning point for him where he really felt like he was "back" as a drummer. The crowd went wild, and his return to the stage was considered a huge success.

Rick has talked about how early on he felt the band was supportive, but had low expectations for him. They told him drumming sounded "good" but didn't give him critical feedback. This made him concerned that they had lowered their expectations for him as the "one-armed drummer." He felt relief and also more respected as a drummer when they started giving him critical feedback, telling him when he did something wrong.

Although he has made it on few "best drummer" lists Rick is highly respected as a drummer by fans and fellow musicians. He cites Aerosmith and The Rolling Stones as Def Leppard's musical peers. He cites drummers Ian Paice, Stuart Copeland, Keith Moon, John Bonham, Simon Kirk, and Gene Krupa as his personal musical influences.

REHAB

In later interviews Rick has reflected on how he never actually underwent rehabilitation after losing his arm. He just sort of pushed through, tried to do it on his own, without getting help from anyone. He has acknowledged that he could have accepted more help than he did after his accident.

He has been heavily involved in recent years with a couple of different organizations for people with Post Traumatic Stress Disorder (PTSD). One is The Raven Drum Foundation, an organization he co-founded with his wife, and other is The Wounded Warrior Project. Both groups create community for veterans and civilians living with, and healing from, PTSD. Through his work with both organizations Rick has begun speaking publicly about his own experiences

with PTSD in order to educate the public and reduce the stigma for PTSD survivors in talking about the experience. He is open about how he self-medicated with drugs and alcohol for many years, as a response to his PTSD. He is not sober now, but says he is drinking less than he used to. He reflects on his anger, and the way his behavior affected his loved ones. It's actually been an interesting process for me to watch those interviews. I had initially kind of written Rick off at one point as a wife beater, and not given him much more thought than that. I see him now as more of a work in progress person. It's clear that even though he was able to play drums again right after losing his arm, there are some other parts of his healing process that are taking much longer to come together.

MEDIA PORTRAYAL

Most of Def Leppard's band photos are set up in a way that hide Rick's missing arm. Usually the photo is taken of his right side, or a bandmate will stand in front of him hiding his left side where his arm would be. On one hand I can see that they want people to focus on the music and not the spectacle of having a one-armed drummer. On the other hand he is not a spectacle, he is a drummer and hiding his left side implies there is something shameful about not having two arms. Journalists often sensationalize his experience, morbidly asking him to re-tell the gripping details of being thrown from a car and losing his arm, and focusing less on his actual craft as a musician.

ROLE MODEL

Being a one-armed drummer of a famous rock band does not necessarily make Rick Allen a role model. Losing an arm doesn't make him a saint. Being able to drum with one arm doesn't make him a genius. Adapting his drum kit doesn't make him the only one. But, he doesn't have to be any of those things for me to like Def Leppard's songs.

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CHUCK CLOSE
(1940-

HIS PORTRAITS

Chuck Close is an innovative portrait maker who got his start in my hometown of Seattle, Washington. The first time I saw one of Chuck's paintings was in a retrospective show of his work at the Seattle Art Museum (SAM). I was there in my wheelchair, with my face pressed as close to the canvas as I could get, asking myself Am I looking at a painting or a photo? He started out using an airbrush to paint huge six-foot tall paintings of people's faces so detailed you could see every pore and eyelash, making you feel like you were looking at a photograph. Later he began working with watercolor to create his realistic style.

In the early 1970s he started to experiment with paintings that use a pixelated style, where a grid is laid down on the canvas and the painting is made square by square. His first piece done in this style is from 1972, Keith/mezzotint; is a portrait of a man done using a mezzotint technique. He developed this style further by filling each square with monochromatic blocks of color. The blocks of color are like individually painted pixels. With these paintings if you are up close it doesn't look like anything except blocks of color. When you stand, or roll, back you see that the blocks of color make a skilled portrait. This style, which he has become quite famous for and he still uses to this day, reminds me of the impressionist paintings of Monet and Renoir.

In 1976 he was asked to contribute a rubber stamp print to a collection distributed by the Museum of Modern Art. His stamp was a small portrait of composer Philip Glass, less than 8 x 7 inches in size. Because he was making that rubber stamp print and had a stamp pad in his studio, he got the idea to experiment with a portrait made solely from fingerprints instead of brushstrokes. After fingerprints he started to take small dots of pulp paper in different shades of grey and white and put them together in a collage style to make portraits. Although a majority of his portraits are oil paintings, he has used many other techniques including wood cut prints, etchings, silkscreens, stencils, and collaged polaroids.

When asked why the people in his paintings are rarely smiling, he has replied that a face expressing one distinct emotion does not provide the same opportunity for observation as a face that expresses multiple emotions at once, or expressions that are ambiguous.

EARLY LIFE

Chuck's dad died when he was eleven years old and he learned at a young age that the thing you think will kill you might be hard, but you won't die. He uses the process of how he makes his paintings as a metaphor for dealing with life's challenging moments, he says to break it down into smaller, manageable pieces to deal with it, like his grids.

After the SAM retrospective I saw a photograph of Chuck in a wheelchair, and I wondered, What is his story? It turns out that his personal story, as well as his process as an artist, are both rich with complexity. Chuck has multiple disabilities, some he has had since childhood and some he acquired later in life. As a young kid he was diagnosed with learning disabilities, so schoolwork was hard. He has also referenced having a neuromuscular condition as a kid that made playing sports difficult. The only class where he excelled beyond his classmates was his art class. He worked very, very hard to improve as an artist because he saw art as his greatest skill. He has said that if it weren't for art, he doesn't know what kind of living he would have been able to make due to his learning disabilities. Chuck also has prosopagnosia, or face blindness, which means he has a hard time

recognizing people by their faces. It is easier for him to recognize a face in two dimensions than it is in three dimensions. Making portraits of friends and family helps him commit faces to memory.

THE EVENT

It was in 1988 when Chuck was at an awards ceremony and began experiencing severe chest pain. He immediately checked himself into a hospital, and what occurred next is what he infamously refers to as "the event." A collapsed spinal artery caused him to have a sudden spinal cord injury, which resulted in him becoming paralyzed from the chest down. He spent eight months of intense rehabilitation determined that he would paint again. In therapy sessions his wife brought in the materials he used to create his paintings, and an adapted setup was created so that he could continue to paint with a paint brush, despite the fact that he had very limited use of his hands. His first painting after the event, Alex II was not large, more like 30 x 36 inches, but the achievement of its completion was enormous. He painted it under the guidance of an occupational therapist while he was still living in the rehab facility. He gave this painting as a gift to his wife at that time, Leslie.

THE EVOLUTION OF HIS WORK

I had some misconceptions about Chuck Close when I started working on this essay about him. First, I assumed that he started experimenting with his painting style out of necessity after his paralysis. I had seen his paintings, the ones which were so detailed they looked like photographs, and at some point later I saw both his abstract portraits on the grid, and also a photograph of him in a wheelchair. I mistakenly assumed that it was only because he physically could not paint in a realistic style anymore that he moved to an abstract style. I was wrong. Chuck has stated in multiple interviews that he does not feel his work has significantly changed during his career, but the materials and the process he uses is what has changed. He points out that he started to experiment with his painting style early on, in the 1970s, twenty years before the event.

What feels so rich about Chuck's story is that there are multiple significant events in his life that influenced him, the event being just one. He has evolved throughout his entire career, not simply after he became quadriplegic. However, In the 2010 biography by Christopher Finch Chuck observed that after the event he started using a brighter color palette than he had before. He thinks this may have been celebratory on his part; he was so grateful for still being able to paint. Another difference he pointed out is that before the event he drew joy from many things other than painting, and some of these things he is no longer able to do. Mowing the lawn, gardening, playing on the beach became pastimes of his former life, and the inability to do those things heightened his desire to do the thing he still could do – paint.

Chuck has credited art with saving his life. When he feels like crap, he paints. It is a form of escape for him, a practice that he says reduces his anxiety.

THE TOOLS OF HIS TRADE

Not only is Chuck a painter and print maker, he is also a photographer. He takes the photographs that serve as the source material for his portraits. Although his subject, the face, is consistent, the materials he uses to make his images are many. He uses paint, ink, pencils, and paper pulp to make his images as well as tools for printmaking, etching, silkscreens, and woodcuts. For painting he wears hand splints with a Velcro harness to control the position of his paintbrush. He uses both hands together to apply paint to his canvas. He has two studios, one in New York City and one at the beach.

For years he used a forklift named Big Joe, in order to reach the tops of his canvases because most of them are so large. He was able to sit on Big Joe, and his workstation was set up there with all his supplies. This system was not ideal for him though, and shortly before the event he adopted a new system commonly



used by theatre set painters, and also by painter Willem de Kooning. The system Chuck switched to has the canvas mounted to an electric frame that can be moved up, down and rotated with the use of a foot pedal. He had a long narrow slot constructed in the floor, flush with the wall, so that a painting could descend into the pit. This system also allows Chuck to be able to sit in his wheelchair and paint a large canvas with easy physical access.

PUBLIC PERSONA

Chuck became famous not only for his distinct painting styles but also for his subject matter. He mainly paints friends, his former wife, daughters, and other family members, but he also painted celebrities including model Kate Moss and former US President Bill Clinton. He has received an enormous amount of acclaim throughout his career, and has featured in over one hundred solo exhibitions.

The media, although it does tell Chuck's story, and often mentions the event, does not overly dwell on this aspect of his life and instead focuses on his craft. Chuck seems comfortable having himself photographed in his wheelchair, and is comfortable talking with the general public about how his health and body have informed his art, and vice versa, how his art has informed his health. In terms of visual representation, there are many photographs of Chuck out there. Most feature just his face - with his iconic glasses, bald head, and salt and pepper facial hair - not the rest of his body or his wheelchair. Given the context of his work and how many self-portraits he has done just of his own face it makes sense.

When I watch or read Chuck's interviews I find the way that he represents himself comforting. It is clear that he knows he who is, and he is comfortable with both his brilliance and his imperfections. We live in a society that tends to pity people with disabilities, putting us in the awkward position of pretending we are completely strong and capable, in order to prove we don't need pity. Chuck complicates this notion by presenting himself as a person that is both strong and vulnerable. He does not have to be a role model. Simply sharing his artistic process, as well as his path of healing, through art, is all he needs to offer.

HIS DAILY PRACTICE AS AN ARTIST

Chuck believes strongly that a painter should not wait until inspiration strikes to make art. That is why he has a consistent practice of painting daily, three hours every morning and three hours every afternoon, seven days a week. During lunch he sometimes goes to the beach or the pool. After work his nurse comes and he'll have a drink, unwind. He applies all the paint to the canvases himself. He has assistants to help lay down his grids, organize his supplies, pay the bills and operate logistics of running a studio. He believes that having mentors and people who encourage you are essential to the practice of making art.

STYLE

Because Chuck has chosen to focus mainly on portraits as his subject matter, he is focused more on what process he will use to make the portrait rather than what his subject will be. He believes in presenting a consistent voice in his art, even if what he is making, or the materials he is using change. He likes making large paintings because he says they're hard for people to ignore. He likes to watch the way people step toward and away from his canvases trying to figure out the best way to view them.

PROBLEM CREATION

Chuck practices a concept I dearly love. He calls it "problem creation." He thinks society is too focused on solving problems. He says that if problems are created, then innovative solutions can be made. He believes that if he pushes himself to a place where he is alone and only he can address the problem posed, then he will be forced to find a creative solution. I like Chuck's perspective on embracing aloneness.

Isolation is such a common experience of disabled people, and here is a man reframing isolation as a stage where creativity can happen.

HOW HE MAKES A PAYCHECK

He makes three paintings a year, on average. His paintings sales are lucrative and he supplements his income with the sale of photographs, prints and other works of his that can be duplicated and sold. At this point he is a multi-millionaire. There is no doubt that his financial wealth has provided him a support system and quality of life that is different than most people of his peers with spinal cord injury. Many who do not share his wealth and the level of family support he received after spinal cord injury are not able to flourish in the ways that Chuck has.

INFLUENCES

Chuck claims to have many creative influences; some that he has named are Andy Warhol, Jackson Pollack, de Kooning, and his grandmother. At a young age he watched his Grandma crochet piles of star shapes. After she had made a bunch of stars she'd take the stars and crochet them together to make bigger pieces, like tablecloths. Watching how she took small things and assembled them together to make big things taught him he could do that, too.

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YAYOI KUSAMA
(1929-

Yayoi Kusama is a Japanese artist who became famous in the 1960s, and later in life has had a resurgence of her popularity and fame as an artist. Major retrospectives of her work have been held all over the world. Many people have labeled her art as modern, experimental, feminist, pop, minimalist. Kusama, who often refers to herself in the third person as "Kusama." calls herself an environmental artist. She is known for her huge installation shows, her sculpture and her enormous paintings. She is also a poet and novelist and has created significant work in film and fashion. A lifelong artist, she started painting and writing prolifically as a young girl, and has produced art and writing consistently throughout her life, and now well into her eighties.

The first time I saw her work was in Paris at the Centre Pompidou. It was a grotesque-looking soft sculpture made out of drippy red gloves titled *My Flower Bed* (1962). The overall shape of it implied an enormous bloody sea creature with tentacles spilling out in piles. It wasn't until I saw a solo exhibition of her work at the Seattle Art Museum that I gained a deeper sense of what influenced her work. I was struck by her installation art sensibilities. One sentence in her artist bio alluded to chronic hallucinations being a source for her art. I was compelled to learn more.

Many people think of dots when they think of Kusama. Polka dots cover many of the things she has made. Obsessive compulsion drives her to create repetitive images, creating fields of canvas and spaces where endless patterns go everywhere, covering everything with no end in sight.

VIOLET OBSESSION

From early childhood, during World War II, Kusama began experiencing visual and aural hallucinations. She has a poem called "Violet obsession" that she wrote about a vast field of flowers outside her family's house. The poem is about her early hallucinations at an early age; she felt a sea of unending flowers was enveloping her. She started drawing images of what she was seeing in order to reduce the fear they caused. These were her first drawings. Thus, the ties between her creativity and her mental experience were entangled from the beginning.

Art critics and psychologists have written extensively about Kusama, speculate that marital strife between her parents was a stressor for Kusama. Her father apparently was cheating on her mother, and her mother, very unhappy, was quite hard on Kusama. As a child therapy was not accepted as it is now, and some of the fears weighing on her, like sex, were taboo. Art became her outlet. She describes her original paintings as intuitive, not born out of a desire to make art persay, but more from a desperate desire to stay alive.

CAME TO THE STATES

Kusama was born and raised in Nagano, Japan to a wealthy, conservative family. Her father was somewhat supportive of her art, but her mother was not. In 1948, after WWII ended, she took a formal course in Kyoto where she was instructed in Nihonga, a style of Japanese painting, but became very unhappy with the rigidity of her training, and dropped out. Yet, she continued to make her own paintings, and was quite prolific. She began exhibiting her work publicly. An early correspondence with American painter Georgia O'Keefe was very influential for Kusama and O'Keefe convinced her to move to New York. In a move that would change her life forever she settled, in 1958 into a New York City apartment, and began exhibiting her work with pop artists Andy Warhol and Claes Oldenburg.



HER INFLUENCES

The art world in NYC was male dominated and competitive. Despite the fact that groundbreaking work was happening in New York in the art world at that time Kusama endorses few influences, although she does admit to admiring the work of painters Jackson Pollack, Pablo Picasso, Vincent Van Gogh and Paul Klein. She actively resists comparisons of her work to that of other artists. In fact, she is eager to point out artists whose work has been influenced by her, including Andy Warhol, her former romantic partner Joseph Cornell, Lucas Samaras, and Marc Jacobs of Louis Vuitton. Kusama rarely speaks of self-doubt. In fact her ego appears quite healthy. "I am an excellent creator." she claims in the aptly titled documentary about her, *I Love Me*.

INFINITY NETS

She started painting net-like patterns on canvases, some as long as 33 feet. Sometimes the patterns would trail from the canvas onto the floor and walls. Kusama has said that when she stands back and lets herself be absorbed into the image, she feel like she is having a hallucination.

OBLITERATION

Kusama has also called herself an obsessional artist. She talks a lot about becoming obliterated. She would paint an infinity net, which would start on the canvas and then flood onto the floor, the furniture, and her. In that way she became obliterated. The painting, the infinity net would become so vast it would cover her, envelop her, encompass her as one with the floor and the room and everything.

MIRROR ROOMS

She started making fantastical mirrored rooms. Some of them had lights, or sculpture inside them, but all of them created a sense of infinite pattern. With the mirrored room, a person can sit in it and see one's self reflected infinitely. Although Kusama was not the only artist of her era who worked in infinity and perspective, her mirror room is a significant artistic contribution.

HAPPENINGS

In the 1960s, she staged dozens of what she called "happenings." These happenings did a lot to increase her fame at the time, although not necessarily her art reputation. They operated similar to a flash mob. She would place an ad in a newspaper, and fans of her work would arrive to a public location. Often they would take off their clothes and play music, while Kusama, would paint polka dots on their naked bodies. At one point she conducted gay marriages with herself the officiant of the ceremonies. She also chose as locations some of New York's most well known Wall Street buildings. Her goal was to obliterate Wall Street with her art. Many of her happenings had an anti-war message.

SEXUALITY

Kusama was raised with the message that sex is shameful. She repeatedly acknowledges both her obsession with sexuality and her fear of it. In the sixties especially, her name became synonymous with sex, because so much of her work at the time explored sexuality. Her fear of sex compelled her to make art that explored sexuality and the body. Many of her happenings included orgies, yet she did not participate. Even though she conducted many weddings, she herself has never been married. Her family attempted to arrange a high-born marriage for her, but she refused. Her attention has been focused on making creative work.

COMPULSION FURNITURE

She sewed hundreds of soft phallus pieces and covered pieces of furniture with them, such as chairs and couches as well as rowboats, overcoats, shoes and ladders. In some of her installation pieces she covered entire rooms, and everything in them with phalluses. Her motivation for creating these pieces

was to obliterate her fear of male sexuality by burying herself in the repetitive process of creating and surrounding herself with hundreds of phalluses.

FASHION

Kusama has an iconic fashion sense. Her early fashions were covered in dots and some had panels missing to expose breasts and genitals. She began selling her avant-garde fashions in 1968 in the "Kusama Corner" at Bloomingdales. In recent years she has designed a cell phone for Japan's KDDI Corporation, artwork for cosmetics by Lancôme, and collaborated with Marc Jacobs on a line of Louis Vuitton clothing and accessories.

Her personal wardrobe palette is almost solely bright shades of red, black, pink, yellow and white. Many of her fabric design are based on patterns from her paintings. Her patterns are modern and bold. In recent years she is often photographed in a red candy colored wig.

WENT BACK TO JAPAN

Eventually Kusama became ill and went back to Japan. Some think her mental health worsened due to a combination of fatigue from excessive media exposure, and because her popularity in the press had begun to wane. She was exhausted, and she was not recognized in Japan by the public the way that she was in New York. Her reception in Japan at that time has been attributed to that she had few connections in Japan's art world and that Japanese culture was quite different than what she had experienced in New York.

ASYLUM

As Kusama tells it she was initially committed to a mental institution by others, and eventually chose to stay as a permanent resident. She has been living in the Seiwa Hospital for the Mentally Ill, a facility in the suburbs of Tokyo, since the 1970s. One block away is the studio where she paints, and stores her archive. She has a team of assistants. Her daily practice is the paint in her studio from 9 am to 6 pm. She has assistants who help keep her work organized, they archive her work, and help her with public appearances, finances and marketing.

MADNESS AS AN ARTISTIC FORCE

Kusama once told an interviewer that she was not interested in curing her mental health problems. Instead she chooses to use them as a force for generating her art. She is comfortable with living in an mental health facility because it gives her the structure and support she needs in order to create her art, which is her primary goal in life.

She is not considered an outsider artist by most critics because she is formally trained and she made a name for herself in the art world before her psychiatric breakdown. Also, her work is informed by her astute understanding of the contemporary art market. Some reviewers call her self-taught because the styles in which she has created art she had no formal training in. Most of the people labeled as "outsider artists" do not have formal training and are making art after being committed to institutions.

CAREER RESURGENCE

Her career was at its slowest in the 1970s and 1980s. During that period she focused on writing and publishing poetry and fiction. It was in 1989, when New York's Center for International Contemporary Arts staged a retrospective was interest revived in her art. She became more active again, mounting several one-woman shows in the US: the Venice Biennale in 1993, where she exhibited a mirrored room filled with her enormous pumpkin sculptures, and in 1998 with a major exhibition at the New York's Museum of Modern Art.

Kusama comments little on her finances or fortune. It is evident that her wealth protects her from many of the poverty-related stresses that most psychiatric

survivors face. She was raised in a wealthy family, and despite the social stigma of living in a mental institution she has accumulated a great deal of financial wealth from her prolific production of creative work. Unlike performance art, which does not often pay well, paintings and sculpture are material objects that sell. The sales of Kusama's work have created a lucrative income for her. In 2008 Christies New York sold a piece of hers for $5.1 million, a record for a living female artist.

MEDIA PORTRAYAL

The best articles about Kusama focus on her craft, her colors, her repeating patterns, and her accomplishments. They capture some essence of her, her mental process, how she approaches her work. Unfortunately, too many journalists fall into the trappings of describing her as garish, or they mistake her use of bright colors and simple shapes as being childlike, funny, or cheerful. It is not Kusama's intention to be these things. She describes her work as an expression of and outlet for her consuming, sometimes torturous visions. Kusama has often been photographed lying on top of her sculptures, curled into them like a little ball, resting in the folds. In these photographs it is clear that art is not only an outlet for Kusama, but a place of respite, a place that nurtures her.

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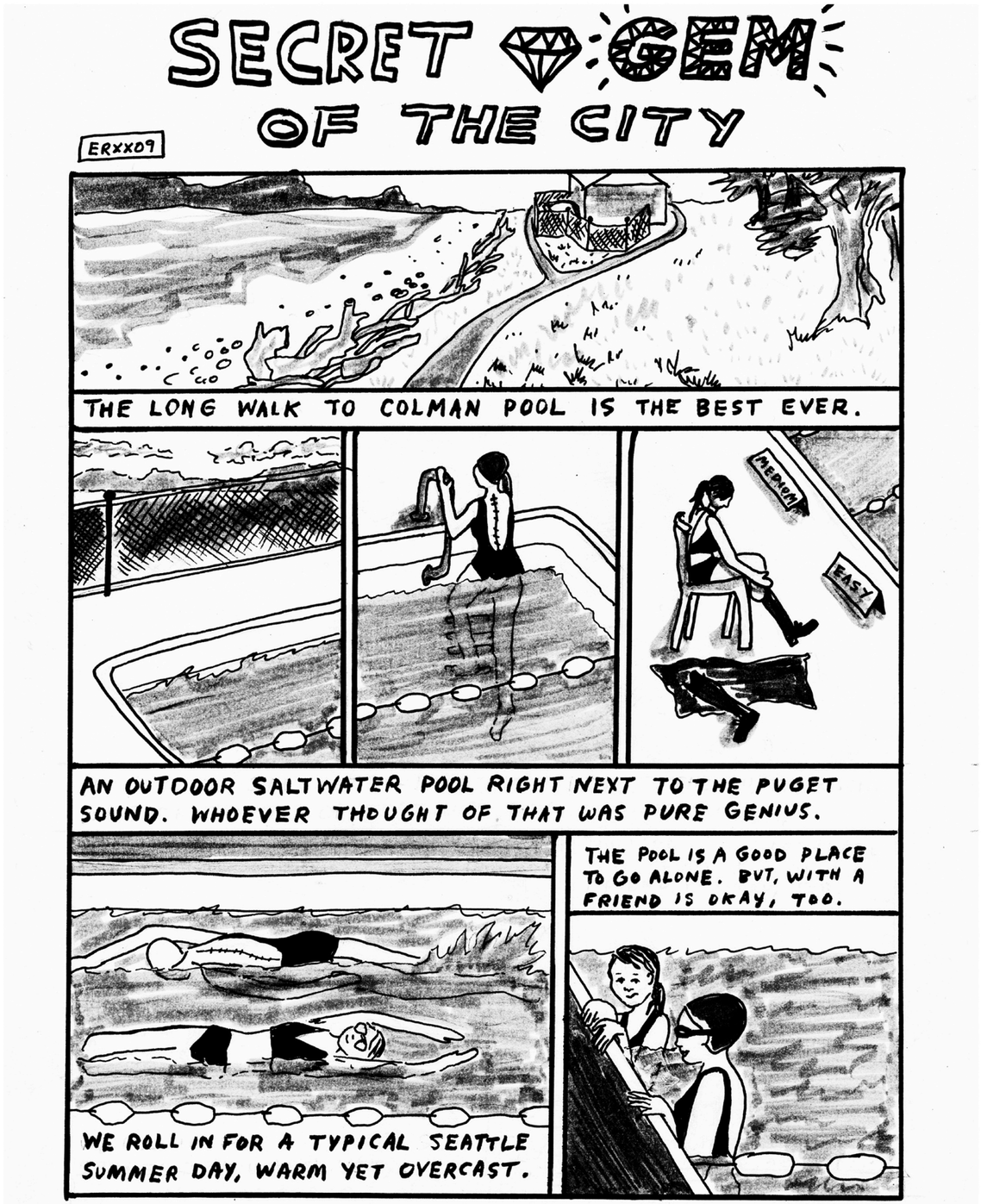
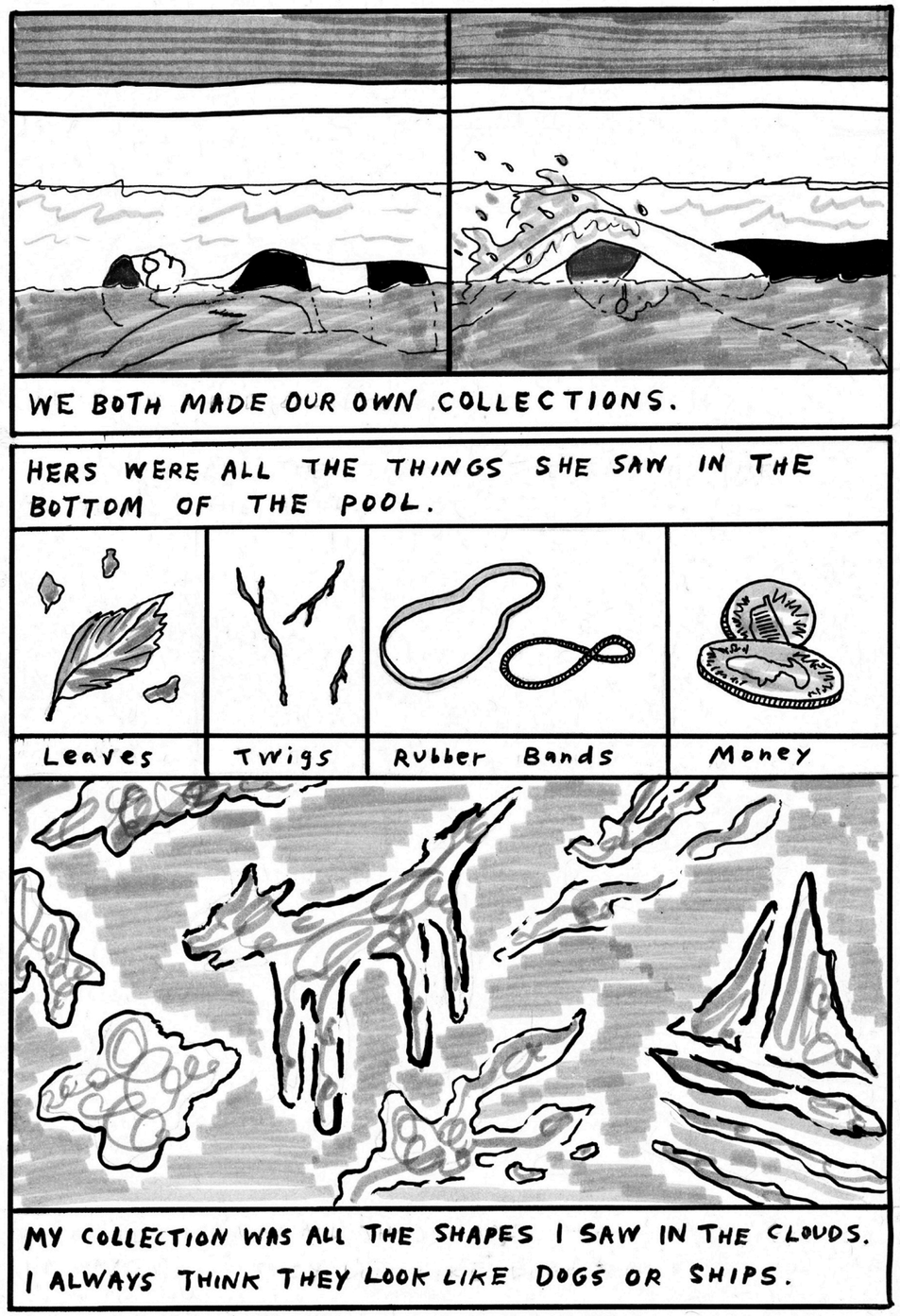
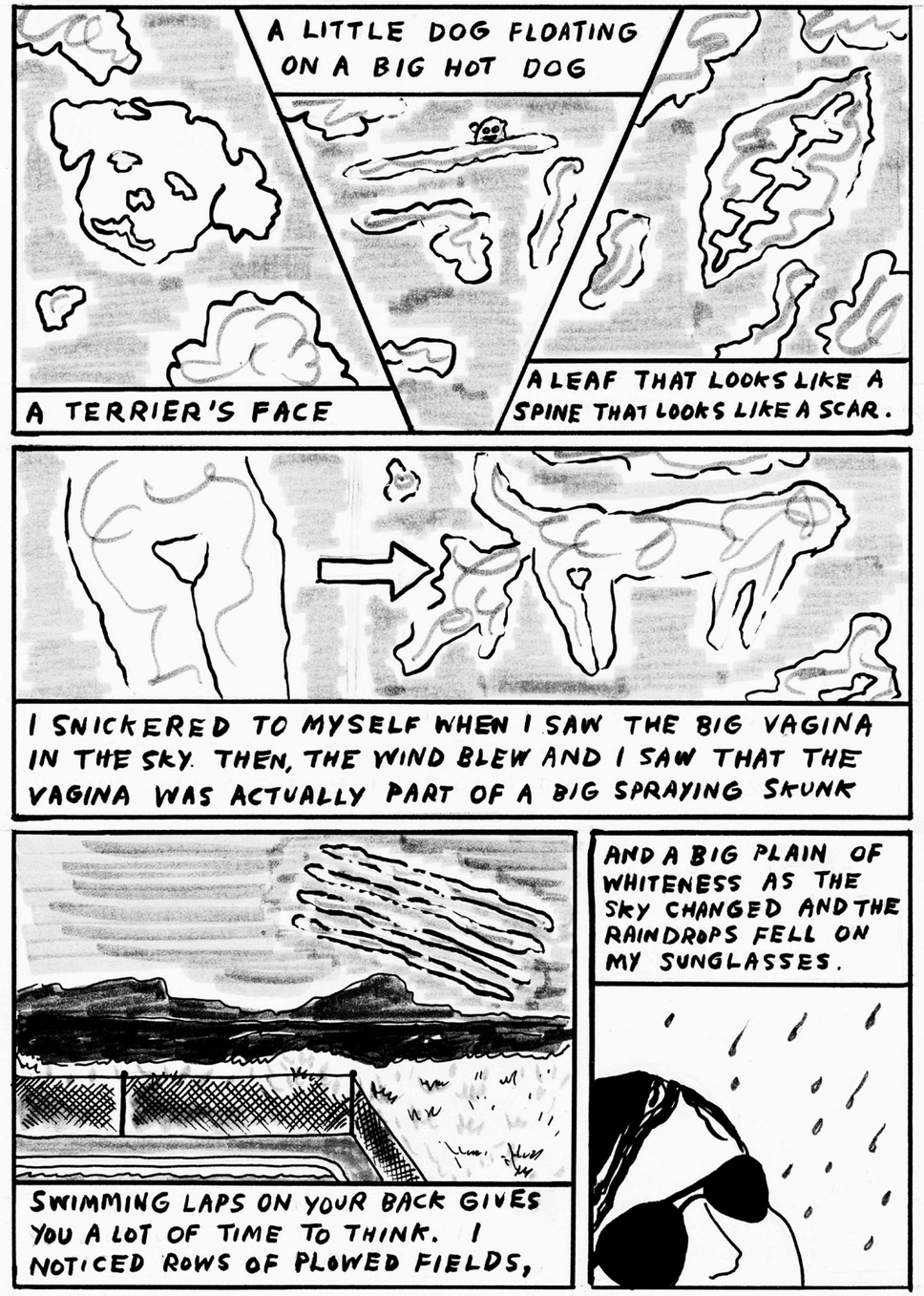



WE BOTH MADE OUR OWN COLLECTIONS.
HERS WERE ALL THE THINGS SHE SAW IN THE BOTTOM OF THE POOL.
Leaves
Twigs
Rubber Bands
Money
MY COLLECTION WAS ALL THE SHAPES I SAW IN THE CLOUDS. I ALWAYS THINK THEY LOOK LIKE DOGS OR SHIPS.


A LITTLE DOG FLOATING ON A BIG HOT DOG
A TERRIER'S FACE
A LEAF THAT LOOKS LIKE A SPINE THAT LOOKS LIKE A SCAR.
I SNICKERED TO MYSELF WHEN I SAW THE BIG VAGINA IN THE SKY. THEN, THE WIND BLEW AND I SAW THAT THE VAGINA WAS ACTUALLY PART OF A BIG SPRAYING SKUNK
SWIMMING LAPS ON YOUR BACK GIVES YOU A LOT OF TIME TO THINK. I NOTICED ROWS OF PLOWED FIELDS,
AND A BIG PLAIN OF WHITENESS AS THE SKY CHANGED AND THE RAINDROPS FELL ON MY SUNGLASSES.

POEM FOR VIC CHESNUTT

Dear Vic,

I didn't know who you were
When you died last week
I'm sure a lot of people
Kill themselves on Christmas day
So, I guess you are not the only one

Your face on the internet
In a little hat and a flannel
Playing songs from your wheelchair
Is a tribute to what you created
Your voice coming through from the grave

I read about you after you died
I listened to your interviews
You made it as a musician and played to millions of people
You recorded fifteen albums and made your living as an artist
All from a wheelchair
Something most of us dream of and never achieve
But what kind of living is it when you die with 70,000 dollars worth of debt to the medical industry for health care that never met your needs anyway

I get it
Living on welfare can be
This double-edged sword
Trading healthcare for any chance to ever live above the poverty line
Who knew that gaining success as a musician
Would turn out to be the dull blade
That would cut you up

I had a dream last night that
I threw myself from a bridge
Luckily I hit some things on the way down that broke my fall
I remember lying on the concrete looking up
When I woke up I knew the dream
Was about you
I guess I didn't realize how much it all affected me until then

I shouldn't be surprised
You're not the first one
And I suppose you won't be the last
Ronald Takaki
Guy Debord
You are among a world-class elite of other gimps, cripples, and broken ones, who threw themselves against the jagged rock of their own pain

Can't pay the bills
Got too many bills

Make too much money
Don't make enough

I want doctors
I hate doctors

It's a confusing life
Even I don't get it
When you say adequate healthcare what is that exactly?
Is this a trick question?

Touch my face
Look into my eyes
Roll me into your covers
Like an animal who can't get enough
Where is this holy place that I feel my body is complete
Does it even exist anywhere?
Not in this waiting room
Not on this clinic bed
Roll that mirror away
It doesn't really help me right now
Writing this poem helps
Writing a song helps

Dear Vic,
A hole was created
When you left
Please don't let me or anyone else
fall through that hole

2010

REASONS I WENT OFF DISABILITY

PRETTY MUCH NO DENTAL COVERAGE

I WAS LIVING UNDER THE POVERTY LINE

YOU ESSENTIALLY CAN NOT WORK WHILE YOU ARE ON IT, EVEN IF YOU TECHNICALLY CAN WORK IN VERY SPECIFIC SITUATIONS

CONSTANTLY LIVING UNDER THE THREAT THAT YOU COULD LOSE COVERAGE OR THAT THEY WILL CUT YOU OFF

YOU HAVE TO REPORT EVERY DETAIL TO THE GOVERNMENT, FOR EXAMPLE THE SOCIAL SECURITY NUMBERS OF ALL YOUR HOUSEMATES

YOU ARE FORCED TO GIVE UP FINANCIAL PRIVACY

YOU ARE FORCED IN VARIOUS SITUATIONS TO DISCLOSE YOUR DISABILITY AND THE FACT THAT YOU ARE ON BENEFITS

YOUR SITUATION BECOMES EVERYONE ELSE'S BUSINESS: WHEN I WAS ON DISABILITY MY BANK, LANDLORD, BOSS AND EVERY HOUSEMATE I HAD KNEW BECAUSE THERE WERE FORMS THEY ALL HAD TO SIGN

YOU SOMETIMES HAVE TO LIE TO THE GOVERNMENT EVEN IF THE LIE IS SMALL (FOR EXAMPLE SHARING FOOD SOMETIMES WITH HOUSEMATES)

CAN'T AFFORD TO LIVE IN ACCESSIBLE HOUSING, SUCH AS A HOUSE WITHOUT STAIRS (IRONIC)

WORKING CAN BE REALLY GOOD FOR A PERSON'S SELF ESTEEM, HAVING RESPONSIBILITIES CAN HELP YOU FEEL CAPABLE, ESPECIALLY IN A JOB YOU LIKE, WHERE YOU ARE SUPPORTED IN THE WORK YOU DO

REASONS TO STAY ON DISABILITY

THE HEALTH CARE COVERAGE (IN ONE YEAR MY LEGS COST MEDICAID AND MEDICARE $20,000 AND THAT DIDN'T INCLUDE THE OTHER HEALTH CARE I NEED)

NOT BEING ABLE TO WORK

NOT HAVING TO WORK!

MORE TIME TO FOCUS ON ART, WRITING AND ACTIVISM

SOMETIMES JUST BECAUSE WE COULD WORK DOESN'T MEAN WE SHOULD WORK, IF WORKING MEANS THAT YOU WILL HAVE TO SUMMON EVERY OUNCE OF STRENGTH AND BRAIN POWER YOU HAVE, LEAVING YOU WITH NOTHING LEFT FOR YOUR ACTUAL LIFE, THEN IT MAY BE MORE MEANINGFUL TO NOT WORK

REASONS WHY I WORK AT A HOSPITAL

I FEEL AT HOME IN THAT ENVIRONMENT

THE WORK STIMULATES MY MIND AND SOUL

IT IS HARD ON MY BODY SOMETIMES, BUT IT ALSO MOTIVATES ME TO BE ACTIVE

I RELATE TO THE CLIENTS, THEY ARE MY PEERS I AM SURROUNDED BY MY PEOPLE (SICK AND DISABLED FOLKS)

I HAVE MET AMAZING PEOPLE AT THE HOSPITAL I WOULD HAVE NEVER MET OTHERWISE, ESPECIALLY PEOPLE WHO ARE SO ILL THEY RARELY LEAVE THEIR HOUSE EXCEPT FOR MEDICAL APPOINTMENTS

I CAN ADVOCATE FOR PEOPLE INSIDE THE MEDICAL INDUSTRIAL COMPLEX

I KNOW HOW TO NAVIGATE THE HEALTHCARE SYSTEM AND I TRY TO OFFER THESE TOOLS TO PEOPLE TO HELP THEM GET WHAT THEY NEED

I WORK WITH PEOPLE IN A VERY INTIMATE SETTING WHERE I CAN OFFER THEM SOMETHING HELPFUL, AND AT THE SAME TIME WITNESS THEIR EXPERIENCE, AND IN GENERAL WITNESS THE EXPANSIVENESS OF THE HUMAN CONDITION AND THE DISABILITY EXPERIENCE

TO BE A HEALING ELEMENT DURING WHAT IS OFTEN AN EXTREMELY INTIMATE AND PIVOTAL TIME OF LIFE FOR ANOTHER PERSON

BEING PART OF THAT HEALING PROCESS IS HEALING FOR ME, BEING PRESENT FOR OTHERS HELPS ME BE PRESENT WITH MYSELF, BEING AROUND PEOPLE WHO ARE HEALING FROM THEIR OWN INJURIES HELPS HEAL MY PTSD

I FEEL FED BY WHAT I DO

OFTEN CLIENTS ARE DEALING WITH REALLY CHALLENGING THINGS AND THEY HAVE PERSPECTIVES AND ATTITUDES THAT ARE HELPFUL FOR ME TO HEAR AND BE AROUND

I AM PAID A LIVING WAGE AND I HAVE HEALTHCARE AND OTHER BENEFITS

REASONS WHY IT'S HARD WORKING AT A HOSPITAL

WORKING IN A FUCKED UP HEALTHCARE SYSTEM THAT IS RULED BY MONEY, NOT BY PROMOTING HEALTH AND EMPOWERMENT FOR ALL PEOPLE

WITNESSING DAILY THE CHALLENGES AND HARDSHIPS ABOUT THE DISABILITY EXPERIENCE

FEELING OVERWHELMED SOMETIME BY HOW MUCH STRUGGLE THERE IS FOR PEOPLE WITIH DISABILITIES TO GET EVEN THEIR BASIC NEEDS MET, MUCH LESS GET THE SUPPORT OR LOVE THEY NEED AND DESERVE

ENCOUNTERING PEOPLE'S INTERNALIZED ABLEISM EVERY DAY EXAMPLE- THE CLIENT DOESN'T WANT TO USE A CANE, CRUTCHES, WHEELCHAIR, ETC. BECAUSE THEY DON'T WANT TO "LOOK" DISABLED, EVEN THOUGH WITHOUT THE CANE OR CRUTCH THEY FALL DOWN, HAVE MORE PAIN, CAN'T LEAVE THE HOUSE, ETC.

PROVIDING HEALTHCARE WITHIN A FUCKED UP SYSTEM AS A PERSON WITH A DISABILITY WITH A CRITIQUE OF CAPITALISM AND THE MEDICAL INDUSTRIAL COMPLEX, CAN FEEL CRAZY MAKING

IT IS OFTEN HARD FOR MY FRIENDS OR COMMUNITY TO UNDERSTAND WHAT I DO OR WHY I DO IT

REASONS WHY SURGERY SUCKS MY MOTHERFUCKING ASS

- BRINGS UP PAST SURGERY TRAUMA SHIT
- FEAR OF FEELING LONELY AND HAVING NO STRUCTURE AFTER SURGERY
- REQUIRES SO MUCH FUCKING PLANNING
- A LOT OF FRIENDS DON'T UNDERSTAND
- HAVE TO ASK COWORKERS AT THE HOSPITAL TO DONATE SICK LEAVE (MAKES ME FEEL LIKE A "CHARITY CASE")
- FEELS LIKE HARSH REPERCUSSIONS
- REMINDS ME HOW FRAGILE I AM
- MAKES ME DOUBT IF I'M TAKING GOOD ENOUGH CARE OF MY BODY (I ACTUALLY THINK I DO TAKE REALLY GOOD CARE OF MY BODY)
- I HAVE TO EDUCATE AND EXPLAIN TO A LOT OF PEOPLE WHAT IS GOING ON

REASONS WHY SURGERY CAN WORK FOR ME

- LESS PAIN (ONCE HEALED)
- MORE COOL SCARS
- TIME OFF WORK!
- MY OWN PERSONAL ARTIST IN RESIDENCE
- CONCENTRATED QUALITY TIME ALONE AND WITH FRIENDS

KINK IN THE ARMOR

It's funny how some clients are quick to point out to me "You're limping!" during a physical therapy session. As if it's such an important discovery it requires blurting. "Yes, I am." is usually what I answer. Sometimes I volunteer "My leg hurts." but not usually more than that. The decision of whether or not to disclose my disability to clients is a nuanced one… To be honest, not everyone can handle it. If I say I have fake legs it can derail the session, the client starts asking a bunch of questions about me, and that's when I need to say "let's keep the focus on you." Or, sometimes I don't disclose because I wonder if the patient or their family will doubt my competence. It is classic behavior for someone to think I'm fully competent until they become aware that I have fake legs. Then, as soon as they know, they start to wonder if I need help opening doors, and bending over to pick things up, etc, etc, etc. There have been a couple times where patients noticed my limp, and once they knew started asking me if I needed to sit down. That would be fine, except for the fact that I am spotting them while they are taking their first steps in rehab, and if I didn't think I was capable of that I wouldn't be a physical therapist.

Sometimes I don't disclose because I feel private and I don't want to talk about it.

In healthcare a construct is set up where the client is completely vulnerable and the provider is powerful. The client's life story and medical history become an open book, but the provider's life remains private. In theory the provider is there to serve the needs of the client, but in many situations that is not how it goes. When a client is too medically ill to make their own decisions, it can be the health care provider who must make decisions. Or, sometimes the client and their family want the provider to make the decisions because they feel overwhelmed and they want someone else with medical knowledge to guide them.

There is also the ego of the provider. They taught us in physical therapy school to appear confident, even when we do not feel confident. They also taught us that when we don't know something, to say "I don't know." and then follow up on it by doing more research or testing, until more is known. Some providers have bravado, thinking they know everything. Some do not know, but are too afraid to admit it for fear of appearing like they don't know what they're doing.

Often, I think that when I reveal my vulnerability, aka my limp, that clients really like it because the power balance is leveled a little bit. It gives them a way to understand me as a person. It feels good to not be the only sick or injured person in the room. That is the upside of disclosing that I have fake legs, to find a point of connection with another person. Especially with clients in a rehab setting, it can be very healing to make those connections, and to meet other people who have been through what you're going through, but who are further down the road.

LEARNED DEPENDENCE

It was in the hospital that I first heard the phrase "learned dependence." For those of you who don't know it, learned dependence is what can happen when a person becomes so accustomed to other people doing things for them that they stop doing the things that they can do. I have also heard this called "learned passivity." People are taught to be passive when everything is done for them, instead of letting them do a thing themself. An example of this happens often during physical therapy sessions. Often clients will expect me to lift them out of bed, to do their physical movements for them, even though they actually have the strength and ability to move on their own. There is often a moment of surprise when I say "I want you to do it for yourself". Many family members and healthcare providers rush to do things for the person or client out of impatience, thinking they can do it faster, or better.

CULTURAL IDEAS OF SICKNESS

I think this happen because our culture has a lot of ideas about sickness, such as sick people can't do things for themselves. Sometimes this is entirely true, sometimes this is partly true, and sometimes this is not true at all, depending on the situation.
As a person with a disability, and as a disability justice activist, I think this is very damaging because there is an inherent message being given to the person that they are not good at doing things for themself.

A lot of times a family will do things for an injured loved one because they think that is how you show love for another person. Often in physical therapy sessions I try to reflect back to the person what they can do.

INTERDEPENDENCE

It was from disability community that I learned about interdependence. About the idea that maybe the goal is not to become independent of one another. Maybe the goal is to become closer to one another. Maybe the goal is to pool our abilities together to lift each other up and get stuff done.

This idea makes sense to me as a person, but because my disability experience has been medicalized since the first moment, it felt disjointed at first to shake the idea of independence as being the ultimate goal.

HOW MUCH "HELP" IS HELPFUL?

In the staff meeting at work recently the topic was psychology in rehab. The newest research on rehabilitation psychology examines the question "How much help is actually helpful? How much is too much help?," and how important encouragement is. Avorn and Langer did a study, a controlled trial, in a nursing home. They took a group of people living in the nursing home and split them into three groups. Each group was given a challenging puzzle to solve. One group was given help, for example: "I think that piece goes here." Another group was given encouragement: "You can do this puzzle!" The third group was given neither help nor encouragement. The study found that out of all three groups, the one that got encouragement had the most correct answers, was faster, improved the most, and had the greatest level of confidence in the ability to do the puzzle. What this study indicates is that doing things for another person is not what will necessarily helps or supports that person the most. Instead, giving encouragement ends up being the most helpful.

Another study from 2012 by McKay tested the way that people respond when they know great things are expected of them, versus when nothing is expected of them. The study looked at walking and balance confidence in older adults. There were two groups, one was the control group, and the other group was given "enhanced expectancy" by being told: "Active people like you, with your experience, usually do very well on this task." The second group, the group that was told positive things were expected of them, developed more confidence in their walking and balance.

Our society promotes a culture where expectations are lowered for people with chronic illness and disability. The lowering of expectations is an unfortunate symptom of ableism. Even more unfortunately a lot of disabled or sick people start to believe that we are less capable than others. The study that emphasizes encouragement touches on the idea that when higher expectations are set, that people will rise to meet those expectations.

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JUDGMENT

An ex of mine is a heroin addict. Even though I love that person it was a very tough road being close to him. I was worried when I went into healthcare that I would be biased against my clients with a history of IV drug use because of my negative personal history with addiction. In school they taught us that if we have a bias we have to be honest about it. Don't pretend you don't have it; that just makes it worse. They taught us to admit our bias, and address it - do whatever we need to do to make sure we give the best healthcare possible to all clients. Regardless of whether or not we like the client. They taught us that after all that, if we still can't give our best care to a client then we need to refer them to another provider who can.

The other day at the hospital they placed me on the cardiac unit, a part of the hospital I don't usually work. Most people there are in one form of heart failure or another. Unlike most patients on that floor my patient was a young girl, just 18. Not totally uncommon here. My hospital tends to get complicated cases.

Just to go for a 15-minute walk around the unit we have to hook up the battery packs to her artificial heart and strap them on her back. The artificial heart is a device implanted in her heart that pumps her blood for her, the motor for it is embedded in her abdomen and the lead wires for it come out her stomach. That's the part that plugs into the wall. To go on the walk we have to plug the battery packs into the lead wires. The nurse is calmly instructing us through all this and she tells us to make sure we watch the battery pack because we only have 45 minutes before it will run down. When it runs down it stops pumping the blood through her heart.
We walk around the unit with the walker, and the nurse following us with a wheelchair. That goes well, so I convince her to walk another round without the walker. She says, "Ok, if that means I don't have to walk after dinner." Ahhh, she's bargaining. I respect that. Her nurse says ok, and we walk again, with me on one side and her mom on the other, each holding her hand. When we're done she says that she's proud of herself.

Back at the computers I ask her nurse why is she in heart failure? From a birth defect? No. It's from drug use. If she's good and stays clean for six months her reward is that her name gets put on the heart transplant list.

I immediately think that heart failure seems like a pretty harsh repercussion for a teenager doing pretty standard stuff like taking drugs. Especially a kid who is working on dealing with her issue and it seems like her life's been pretty tough in other ways. Her chart said she has a history of sexual assault. Obviously life is not always fair and taking drugs is a risky activity. A lot of kids do things that are risky not thinking that their heart might stop working. It made me think that it would be pretty easy for some people to judge this girl. She brought it on herself. But, what is the point of that. She can still pull it together to get a transplant. Plus, it's unfair to judge clients, obviously I am privy to a lot of highly intimate information about them, and they have very little information about me.

A complicated series of emotions follows for me in these situations. Instead of thinking about my ex, the one who struggles with addiction, I think about myself. This is the hard part to write about. It's easier to write about judging other people. But, it's judgment of myself that comes up the most when I encounter clients who are in situations that are "easy" to judge.

Sometimes I think it's almost better to have a hard life when you're young, because then you never take good things for granted. You always know how fucked up life can get at any moment, so you savour what you've got. Maybe it's the jaded part of me that thinks that, the damaged part of me. But maybe that damaged part of me is the wise part of me. I consider this girl and I think how most of us have made choices that should have had repercussions, but didn't, for whatever reason. And here is this girl suffering something so harsh Obviously, life is not fair. But, sometimes it is really not fair. Maybe I just relate to her because my own life at 18 was filled with consequences.

WHAT I LEARNED ABOUT MYSELF WHEN I WENT OFF BENEFITS

I was on disability benefits for ten years and then went off of it. As an anarchist who opposes government it felt really good to be out from under the thumb of the state. I was so fried from all the letters I got from Social Security, threatening to suspend my benefits if I missed a standard meeting. Of course I won't miss the meeting, I always thought. As if I'd want to lose my monthly check and medical coupon. As a disabled person who had little chance of making a living and was surviving under the poverty line, it was extremely scary to give up the income and healthcare that I received on benefits. Not that Medicare covered vision or dental or a whole bunch of other things, but it did cover everything related to my legs, and that mattered. I have no idea how many hundreds of thousands of dollars that cost the state in those ten years. Three surgeries, dozens of visits, and at least several pairs of legs were made.

After my train accident a trust fund for medical expenses was set up for me by the moms of my closest high school friends. People I knew, and didn't know, donated to the trust fund with the goal of covering my medical needs at the time. Because I was eventually able to get on Medicaid all my bills were covered retroactively, so instead the donations from the trust fund sat in a bank account. An account with very specific parameters around it, parameters that would not jeopardize my disability benefits. Years later, when I went off disability, the fund was made available to me, and I used it for the down payment of our house. It's funny how things work out. In a way it felt like the accident paid my way to owning a house.

During the years I was on benefits I tried to figure out how to get back on my feet again, literally and figuratively. I had few options for being able to work. Unless you are trained to do a skilled job, most options involve manual labor, or at least a lot of standing or walking. Those options don't work for me. So, I got a bunch of state funding and went to school for eight years to train for a skilled job. I picked physical therapy because it meant a stable job with healthcare. It also meant that I get to work with other people with disabilities, aka "my people."

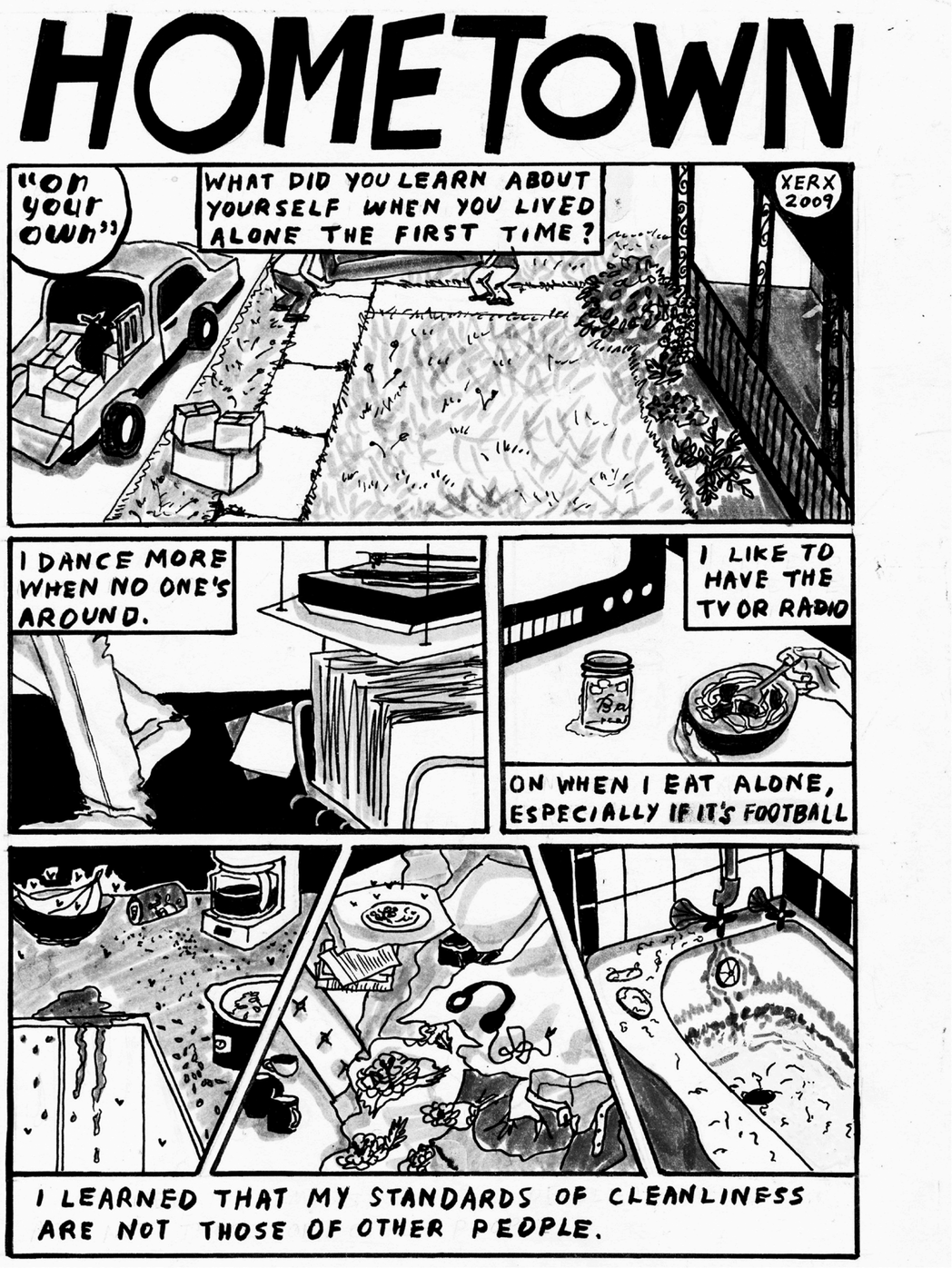
When I started working I went off disability and for the first time in my life I was making more than $8,000 a year. Actually, I was making a comfortable middle class wage. One of the first things I did was buy myself a new bed, and get myself a yoga membership so I could exercise in an accessible place. I started paying off my school debt. If there was a sliding scale I started paying at the top of it, instead of the bottom. I was able to donate to the local grassroots groups I believed in. And, I went on vacation. Several years later I bought a house with a friend of mine. It's complicated. I make more money now than I ever have. I make more money than most

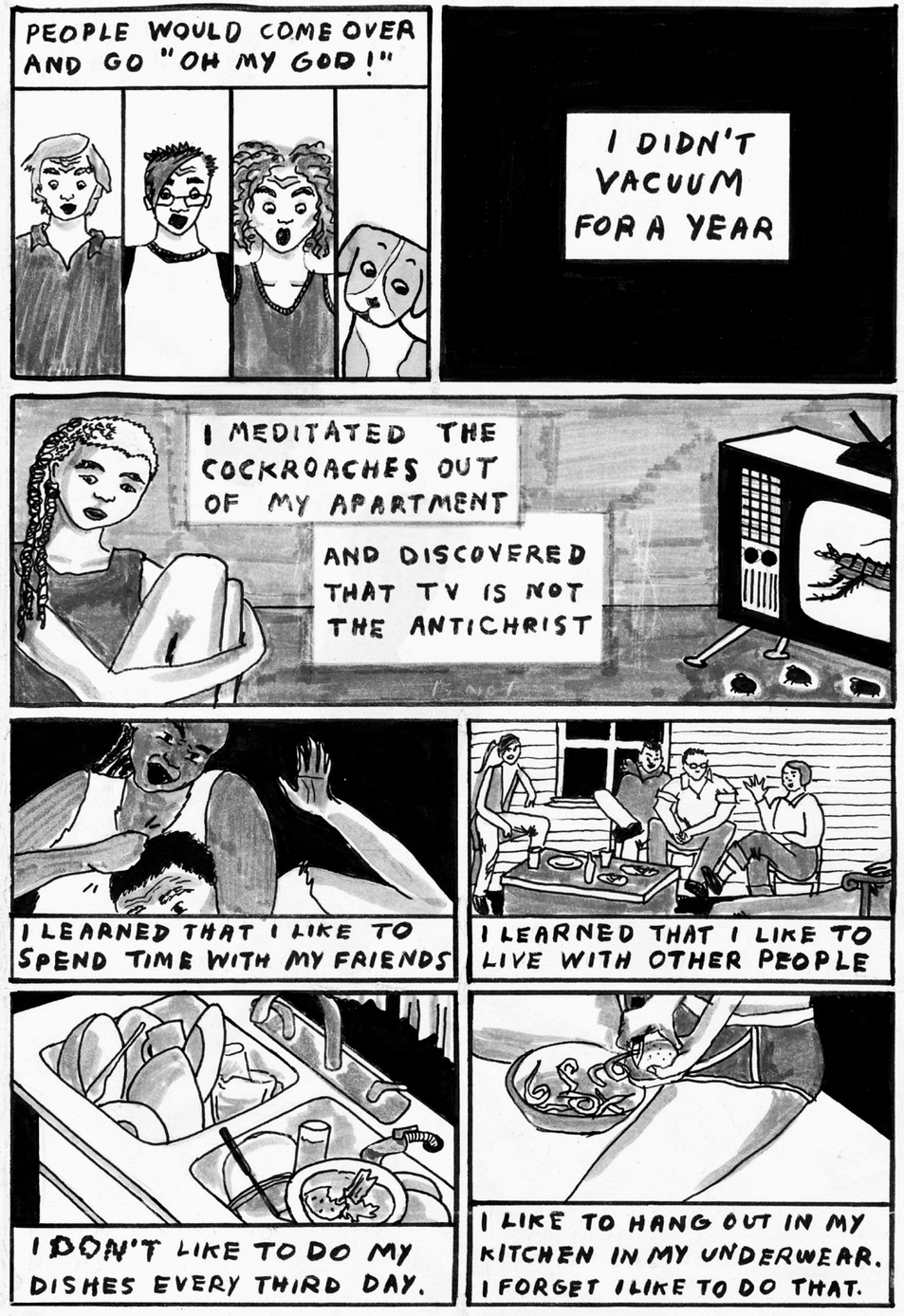
people in my family, including my parents. Most of my family has never been to college. Most of my family works in manual labor, in the trades. My mom cleaned houses; my dad was a welder and a bricklayer. Both of them peaked in their earning potential in their 40s, and it went downhill after that, after their ability to do physical labor waned as they aged. Growing up I knew we didn't have a lot of money but my parents had stable work, and they owned their house, so we had a lot in that sense. It's complicated now because I feel very fragile in my ability to work. I have used all of my sick leave and vacation days from a combination of surgeries and times that I couldn't walk. What I am experiencing is a cultural issue. Most disabled people aren't working, either because they are not able to work, or because places won't hire them due to discrimination.

A few months ago I was crying in my doctor's office. "Do you think I'm doing too much?" I asked her. I had another infected cyst on my leg and couldn't work for a week. If it healed I could go back to work. If it didn't heal I would need another surgery. As a person with a disability I think a lot about the toll my work takes on my mind and body. My coworkers in their 50s are like, "Oh yah, that's probably a good thing to start thinking about," meaning that I am more worried about it than they are. I'm 35 and I look at what my coworkers in their 60s are doing, what specialties and roles they've taken on at work. Most of them involve high skill, and low physical requirements. I have started to focus my own skills in that direction.

Charles Dickens wrote a story called *Little Dorrit*. In it the main characters find themselves in a state of changing class status throughout the book. Extremely wealthy characters lose all their money and have to learn to live with nothing. Beggars who have nothing discover they are heirs to vast fortunes and become rich overnight. Maybe the most fascinating aspect of this story is how changes in class status affect the way the characters relate to one another. As the story is written they can really only relate to each other if they are both poor, or both rich, at the same time.

Poverty is a huge part of the disability experience for so many people. Often, I feel acutely my privilege as someone who has been able to find work and go off benefits. I know that my skin privilege as a white person has a lot to do with my ability to make it through school and get a job. My sense of privilege around being able to work has given me a strong sense of responsibility to share my resources with my community. That doesn't just mean money, but also what I have learned about how to work the system.





SASCHA ALTMAN DUBRUL

Sascha Altman DuBrul is a bicoastal writer, activist and gardener, as well as co-founder of the Icarus Project, a radical mental health organization run by and for people working towards wellness. He is also a dear friend of mine. Sascha and I met at an activist conference on the west coast, when I was nineteen. We traded zines, mine was an early issue of Ring of Fire*, and his was an anthology of writing and comics about dreams. It has been since we met that he co-founded the Icarus Project and I co-founded the Seattle Disability Justice Collective. The conversations offered here took place over a period of several years. Sascha and I share some similar viewpoints but we do not always agree or understand each other. These conversations served as a bridge for us to understand each other more, and over the years our conversations have evolved as we have changed as individuals. We talked about the long-term challenges of founding an organization, the challenges of making connections between disability and mental health, and what gives us hope. In March 2010 we hung out in his kitchen in Berkeley, California while he made us lunch. In April 2013 we recorded a follow up conversation when he was on a book tour with Icarus co-founder and author Jacks McNamara. We hung out in my kitchen in Seattle, Washington while I made us breakfast.*

MARCH 2010

SASCHA - Ok, right now I'm cooking up some collard greens from the seed swap that happened the other night that someone brought. I guess you know for years food has been the reoccurring theme in my life. As a city kid I figured out a good way to organize people was through food. And even after years of doing mental health activism it still, I feel like, comes back to food. I feel like that with my mental health and vegetables. [laughter] On a very personal level. It's interesting where we come from, what got us interested in doing the things that we do. For me, growing up in a real alienated environment without much of a family, that's a huge part about why I sought out other people, and sought out community. You can look at the history of the Icarus Project, and what were we doing? We were taking the useful threads of anarchist community organizing and putting them in a way that could benefit other people who are struggling with mental health issues and I think in general, whatever it is that one struggles with in the world.

I am diagnosed with… it's terrible the modern language we use to talk about this stuff! In the modern language I am diagnosed bipolar I with psychotic features. [laughter] That's the language that they give us to make sense of our life experiences, you know? That's what I've been told is my lifelong illness, I'm always going to struggle with it, and if I don't believe that, I'm just deluding myself. So, how do you take that? And turn that into something positive? You can just ignore it and pretend that its not there and say that they're just full of shit. Or, you could say, "Well, you know, actually a lot of what you're saying there is clearly some truth in it that I recognize." But, how do we switch sides of this so that we're not the disempowered ones anymore? So we're actually the ones with the power, making the decisions about how to do what we need to do for our lives? Very tricky. Very tricky.

ICARUS PROJECT

RING OF FIRE – If you were going to describe what Icarus Project is to people who don't know, how would you describe it?

S - I would say that it's a radical community mental health support network of folks. The Icarus Project started off as two people starting a website in 2002 trying to create space for alternative voices of visions of what gets considered mental health and mental

illness. It rapidly grew. It started off as just my friend Jacks [McNamara, the co-founder of Icarus Project] and I. After a year we published this book called *Navigating the Space Between Brilliance and Madness*. That had the voices of all these different people who had been writing on our forums and stuff, and that really helped to bring together a community of folks. From there we put out this other little booklet/project thing called *Friends Make the Best Medicine: A Guide to Creating Community Mental Health Support Networks*, and then people started these Icarus Project groups all over the place. The idea of it all is really to create a space where people could feel safe to talk about the issues that they were having.

Back in 2005 we officially became a collective. Jacks and I both had specific kinds of experiences that we had come from. We were both folks who were diagnosed with bipolar disorder and came from economically privileged backgrounds, and so we had particular worldview. Some of the people who came on later were way more critical of psychiatry than we were. We are both people who take psychiatric meds; they work for us. But, the fact is that we are living in these really scary times where tons of people are getting diagnosed with all kinds of things and getting put on drugs that they don't need to be put on. There's all kinds of people who are put on drugs who don't know how to get off the drugs.

So, one of the important things that happened was we published a harm reduction guide to coming off of psychiatric meds, and I think that whole tension of are we pro-psychiatry? are we anti-psychiatry? is something that's kind of woven into the knot of what Icarus Project is. People all over the world are identifying with this thing that we started, which really just comes from a vision of seeing the struggles that we have as dangerous gifts, rather than diseases or disorders.

DANGEROUS GIFTS

ROF - Can you say a little more specifically what are "dangerous gifts?"

S - Dangerous gifts… What falls under dangerous gifts are anything that is seen in society as being an illness or disease. Whether it's bipolar disorder, or obsessive compulsive disorder, or schizophrenia. By saying dangerous gifts there is inherently this critique of the society we are living in, well, the society says that we are sick. But, it's important to get it really clear from the start that the society that we live in is really sick. If we start from that place, things look really different. What gets considered schizophrenia in this culture - in another culture it would look really different. And, that's really important.

ROF - Can you explain what is the gift part?

People all over the world are identifying with this thing that we started, which really just comes from a vision of seeing the struggles that we have as dangerous gifts, rather than diseases or disorders.

S - The gift part, it looks different in different ways. It's the thing that's gonna kill you, or the thing that's gonna seemingly making you suffer, is the same thing that going to allow you be able to understand things that other people haven't seen. You've talked about how because of what happened to you when you were 18 years old, you were forced to become an adult faster and learn how to take care of yourself at a time when your friends were still partying, and you were in a different stage in your life. So, how that applies to me is something that you know. If I don't take care of myself I end up in the hospital. And what does that do? It forces me to take really good care of myself. It forces me to have a very set routine about how I do things, which is not what I was hoping for in my twenties. [laughter] That wasn't the gift that I was hoping to be

given, but lo and behold I feel like my sense of self, my relationship to my feelings, my sense of empathy, my ability to connect with others who are suffering and who struggle - these are are tricky gifts. They're not like the nice gifts you get from your grandma. It's like the gift that makes you have to work, I guess.

ROF - Can you say more about what Icarus has become in more recent years?

S - When, I think about the Icarus Project right now, I'm really interested in helping to tell the story of it. Like if you were to go on our website and look at the discussion forums, there are thousands of threads on there. I see future projects coming out of all of that work and all of that community.

LONGTERM CHALLENGES OF BEING A FOUNDER

ROF - Talk about what else you're doing. It seems like you're in a different place right now.

S - A lot of what it came down to was that I'd been so obsessed with the organization for so long that the only people who I was hanging out with were people who were involved in the organization. It made me start looking at all kinds of dynamics, not just in Icarus, but in the movement in general. One of the things was the way that my life changed from being in my early twenties and then in my late twenties and early thirties, and going from being a guy who was traveling around and writing stories to someone who was running an organization. I suddenly had way more power than I'd ever had before. It was super uncomfortable and made it so that it was really hard to just hang out with people.

…my life changed from being in my early twenties and then in my late twenties and early thirties, and going from being a guy who was traveling around and writing stories to someone who was running an organization. I suddenly had way more power than I'd ever had before. It was super uncomfortable..

ROF - It sounds like there were some founder dynamics going on, like because you were a founder that came with it certain power dynamics that made the dynamics around you different than dynamics around other people in the group. Was it painful for you to be receiving so much public critique from people in your organization when that had become your whole social network?

S - Yah. People who are charismatic and people who are getting people together and stuff - it's very hard to be in that role and to be just like one of the people.

ROF - Right. Like being the face of an organization, so you can help promote it and people connect to it, but then ultimately still want to be able to participate, and like you said get support. It seems like that position does open you up to a lot of critique, and to receiving critique. Umm… has the critique been helpful, though? I mean, it sounds like its been painful, but has it also been helpful?

S - Well, I think in general that, no matter what position, you are forced to look at the power that you hold. I'm learning to understand not just for myself, but societally where that comes from. It took me leaving the organization, and basically I lost my mind, you know? It all kind of came out of the same thing… it was just kind of my own bad coping, undeveloped coping skills. I went to a place where I didn't know anyone, so I could get some sense of what happened, and then came back to my community.

ROF – It sounds like some of what you're working on now is an internal process. And maybe you're continuing the process of what you accomplished with Icarus plus these other pieces of your life, and now going in some other directions.

S - A lot of what I'm doing now, it starts with this foundation of how do I best take care of myself, for real, you know? And the kind of relationships I've had on a daily basis with my housemates and my friends, as opposed to working in an organization.

A lot of what I'm doing now, it starts with this foundation of how do I best take care of myself, for real, you know?

I'm spending a lot of time looking at history. How things have happened before and, in a calculated way, trying to figure out how to make things better. Looking at the radical mental health movement, and trying to figure out what the future of it is. I had this kind of harsh realization when I was living at that yoga ashram last year where I was thinking about the idea of mad pride, which is really kind of a rallying cry for a lot of people in the Icarus world, and realizing that really neither madness nor pride are things that I'm interested in cultivating. [laughter]

ROF - I guess that speaks for itself.

LEARNING THE HISTORY OF PSYCHIATRY

S - One of the pieces of our recent history that I think is very interesting is in the 1960s and 1970s there was what was called the Human Potential Movement. That came out of Aldous Huxley, who wrote Brave New World, he was a real visionary. And there was a whole movement of Abraham Maxwell and Joseph Campbell and Alan Watts, and all of these interesting characters that were really interested in evolving the culture. There was this real mix of eastern spirituality and western psychotherapy - what ended up happening to it for the most part was is it ended up becoming the New Age movement. Any kind of politics there were got sucked out of it, but I feel like there's some really good history there and I'm really interested in excavating the useful pieces.

ROF - What have you learned so far that you're excited about?

S - In general, in the 21st century, I think we're living in the midst of what is considered the biopsychiatric model of mental health; the idea that our mental health is based on brain chemicals. That you can take some chemicals and it'll change your brain. And, that if you're chemically imbalanced, you can get more balanced. If you look at the research there is really no scientific evidence of this, it really has way more to do with pharmaceutical companies and their ideas of money and that really changed in 1980. In 1980 was when the DSM III came out and that was the big shift that happened. Shortly before that, there was all of this influence by the Human Potential Movement, and what is considered Existential Humanistic Psychology, there was all kinds of community mental health programs, there was all kinds of funding which got cut when Reagan came into power.

ROF - It sounds like you're reading a lot of books.

S - Thankfully, because I'm here in the Bay Area of California, this history is recent and there's all these people who are still alive who were a part of that movement. It's really interesting if you talk to anyone who became a psychiatrist before 1980, especially the one who became psychiatrists in the late 1970s. Their view of what psychiatry is so different than psychiatrists who are coming out now, who are just learning this straight heavy pseudo science.

ROF - Tell me about that. Is your take that post 1980 psychiatrists are just really medication focused, and focused on this biopsychiatric model? And before 1980 it looked really different?

S – No, the history of psychiatry is not a pretty one, but there was actually talk therapy. That, like, doesn't exist anymore. It's interesting, the ideas of Freud who was so problematic, but at least was looking at the human being as something with feelings and

emotions. With the biomedical model the whole idea is that they wanted to create a science that was a hard science, you know? That could be proved. Because they were getting so much criticism in the 70s from the anti-psychiatry movement. Because the counter culture was so coming down on psychiatry they ended up very slippery, like "No, we've changed psychiatry, now it's scientifically proven." And it just happened to come at the same time that Reagan came into office and the conservative backlash to all the social progressive movements of the 60s and 70s, and I feel like that's really telling.

CLAIMING DISABILITY

S - I want to ask you about the idea of disability, where do you think it's harmful and where do you think it might be helpful?

ROF – You talked about how you're going to this deeper level of interpersonal work and learning your history. I kind of just did the same thing. I just took this six-week disability studies class that was offered in Seattle to the public. What was nice is there were other people in the class who were kind of like me, who had been thinking about it for a really long time, who have a lot of analysis and it was cool to engage with each other and go even deeper on something I was already pretty deep on. Actually, it was kind of amazing, and I got a lot out of it. Anyway, in that class there was a lot of talk about what is disability and there's hundreds of models that define it and they're all different.

...disabled activists have reclaimed the word disability, and have redefined it as a political and cultural identity... The word, when used this way, rejects the medical idea of disability...

S- What I've thought about for years is there's the kind of language I use to talk about myself in a doctor's office, and then there's the kind of language I use to talk about myself to my friends, and it's just really different language, you know? I was just learning about the Marranos, the Jews in Spain who had to hide that they were Jews. When they were alone, when they were just with their families, they would practice Jewish rituals, but on the outside they were Christians. That idea of dual sets of who you are, you know? And I was thinking about how for people who are in the situation I'm in if you're going to navigate the mental health system you're going to have to speak the medical language. But, it's one thing to speak that language, it's another thing to believe it. Often with disability I see identifying as disabled comes in handy if you're trying to get benefits, if you're trying to get services, but I don't know where that fits. That's why I'm asking you the question.

ROF – This class that I took, very much was framing the idea that disabled activists have reclaimed the word disability, and have redefined it as a political and cultural identity that people can take pride in. Some people call this a cultural model of disability. The word disability, when used this way, rejects the medical idea of disability, the one that says disability is a flaw of the individual and that it can be cured with science. The word disabled is very limiting in itself, but it's better than a lot of alternatives. It's also complicated by this whole question around "Is the disability solely based in what's going on for the person, or is it based in the environment around the person, or is it both?" Does that make sense?

S – Yah.

ROF – The word disabled is somewhat similar to a word like feminist or any label you would put on yourself. In a lot of ways it's coming from a good place. But that doesn't mean everyone is going to relate to it. Everyone should be able to self-identify.

I think because I work all day long with people I perceive as having disabilities, I see a lot of internalized ableism and how it plays out. A lot of people are in

denial about what's going on with their health, and I think that state of denial can be really harmful. When people aren't fully accepting what's going on for them they may not practice self care in the ways they really do need. I see the way that it affects people's quality of life and the choices that they make.

It's helpful sometimes in a doctor's office or at social security, to use the term disability because it's the language of the system. Thinking of yourself as disabled may not be helpful, in terms of your idea of yourself as a person, especially if it's thought of as a medical problem. The flipside around claiming disability is it can be incredibly empowering to claim pride in the thing that makes you different, and to push back on shame. Our society is full of shame, especially for having any kind of mental, physical or emotional difference. Claiming disability in a political way is one way to connect yourself to a political movement that says it's not you that had a problem, it's our society that doesn't understand difference. A lot of what the movement is about is educating each other about our difference, about why things like universal design are so essential, and making connections between things like ability, economic status, race, gender and all of that.

UNIVERSAL DESIGN

S- What's universal design?

ROF – Ok, so universal design is the idea that, for example, if you design a house in a way where everyone can access everything, then anyone can use it and no one is disabled by the environment of the house. It's a very simple concept, but it involves intention and thoughtfulness before the thing is even being built. And a lot of people don't have that, to be blunt! So, universal design ends up being an exception to the rule, instead of the way that everything is done.



A lot of shows that get put on, poetry readings, play parties, birthday parties – these things happens in places that disabled people can't attend because they were not designed in an accessible way. If they were universally accessible, everyone could attend.

FINDING OUR COMMONALITY

ROF - So much organizing gets done around medical diagnosis, you know? Like, here's the Deaf community, here's the hard of hearing community, here's a group for people with spinal cord injuries, here's a group for people with environmental illness, here's one for psychiatric survivors, here's one for people who are bipolar. It's very diagnosis-specific. And often, because of internalized ableism, there is a lot of other-ing that goes on. Like that scene in Murderball where the Paralympic athletes make fun of the Special Olympics "We're not like them." I relate a lot to my friends who are Deaf, blind, crazy, and in wheelchairs. I don't have that many friends who are amputees. So, to me, I see us as being all very unique with some of us having totally different ability experiences, but still there's this commonality. Maybe I focus on that because I want more community. I want more of a movement. Honestly, I think disability isn't something people are talking about enough. It's not on their radar, they're not aware. And it ends up being very painful for those of us who are aware. It makes life harder in some ways. The language isn't so important as maybe the dawn of realization about connection between people, or something?

There are so many commonalities we share… Isolation is a big one. A lot of our lives are really tied up in the medical industrial complex. Many of us experience pain or the inability to do certain things that we really want to do, and then we need help. Asking for help - even the word help is really loaded – that's another one of the commonalities that we share. The challenges of being able to work, to find work, to live above the poverty line, those are things a lot of us share. And cultural stuff, like the culture of needing to plan ahead a lot, for access, just for everyday things.

YOUTH CULTURE, MENTAL HEALTH AND DISABILITY

ROF - The question I have for you is how do you perceive the radical mental health movement in relation to disability movements?

S – Well, there's clearly a whole lot of overlap. There's this saying "Nothing about us without us." I think that comes from the disability movement, and I think that's something the mental health movement uses. Y'know? I feel like there's a lot of overlap. I think a lot of it is the overlap of the academics who are writing and the people who are on the ground doing organizing and creating spaces for dialogues to happen.

A lot of what we talk about in the Icarus Project - which I feel like, is in the mix of the forefront of what is the radical mental health movement - is what are societal conceptions of what we want, and then there's what do we want for ourselves. There was a WHO (World Health Organization) study done and they determined the billions of dollars every year that the mental illness was losing because people weren't going to work. Now, from the Icarus Project's perspective that's a lot of bullshit. How are you possibly come up with a statistic like that? And, are you going to define our health in terms of do we go to work every day, when what work means for many people is something that will make them unhealthy.
I gotta say this is not the happy answer, but I found after a number of years of organizing with Icarus, that what we are using to define ourselves with, whether it is dangerous gifts or something romantic, saying that we are mentally disabled has not been empowering… I like what you're saying about finding reasons for people to come together for something much larger. Clearly that's where the future is at for these movements that we're a part of, figuring out ways for people to connect and feel like they're a part of something.

ROF - This subculture that we're part of, this activist artist subculture, is very much a youth culture that is very ableist and very not disability friendly. When I

see this radical mental health movement happening, which I think is so exciting, I see a lot of young people getting on board with that who haven't made connections with other kinds of ableism. I'm wishing more connections could be made between what we're all doing.

WELLNESS MAPS

S – There's a lot of power in that desire to bring people together. That's what brings people together … Ok, here's something that comes to mind. Remember I sent you that project I was working on, the wellness map?

ROF – Yah, I love that idea!

S – So, the idea with those wellness maps, it's not just that you're going to create a document for yourself so you're going to be able to know and remember how to take care of yourself, the idea is that you share that with the people you are close to in your life and then they also know. It's a very vulnerable position you're putting yourself in, but you do it out of this kind of necessity. The thing I really like about it is it puts the person who is struggling in the center and it's this focal point that brings people together. That's the kind of commonality I'm hearing in what you're saying. Part of what I'm hearing is that people don't understand if people are not sensitized to it. There's some level of there's an education process within a community that has to go on for people to understand what's going on. It seems like an important commonality is how in the modern society that we live in, there's so much emphasis on productivity and working that people who don't fit into that model get pushed to the sidelines.

I grew up in an environment that was like a very high-powered kind of environment my parents were both super hard working, and I was supposed to be like that. When I started hanging out with punks it was a revelation. There's aspects of the anarchist, activist, artist community, as a youth culture, that are really awesome, and aspects that are not. Some of the awesome aspects are the freak community that happens, where people feel comfortable being different, and there's something in that you don't see in other aspects of our society.

Then, when I saw Sins invalid [the disability justice performance project in California] it was like wow, what an incredible space. How would you create a space like this? How could you do it more? What would that look like?

We are really interested in what it would look like to build a movement that creates the space for intergenerational mentorship. And where once people are healthy and doing well, they stick around.

APRIL 2013

ICARUS PROJECT AFTER TEN YEARS

ROF - Are you happy with where Icarus is at, now that it's been around for ten years?

S - Jacks and I have spent a lot of time thinking about embodied leadership, in relationship to social justice movements and the Icarus Project, in particular. I have been thinking a lot about this. We've spent a lot of time in reflection about what has worked and what hasn't worked, in the organization and in our community.

One striking reflection is that people are often drawn to the Icarus Project when they are in a state of crisis and once they're healthy they leave. We are really interested in what it would look like to build a movement that creates the space for intergenerational mentorship. And where once people are healthy and doing well, they stick around.

WHAT IS WELLNESS?

ROF – You've been talking a lot about what 'wellness' looks like. What does wellness mean to you?

S – A key piece of this work, for me, revolves around this idea that we can try to talk about mental illness, but it doesn't really make any sense until we talk about mental health. Meaning, we have to understand for ourselves what it means to be healthy before we talk about what it means to be mentally unhealthy. We can talk about our own personal wellness and say: 'Ok, well, these are the signs I know that I'm well. Or, we can look at a group of friends and say: 'What are the signs that a group of friends are well? What are the signs that a neighborhood is well?' And then, 'What are the warning signs that things are not so well? What do things look like when they get into crisis?' But, starting at this place of health, for ourselves. And, maybe your idea of health and my idea of health are different. Maybe society's idea of what healthy is, is different than what my idea of healthy is.

A key piece of this work, for me, revolves around this idea that we can try to talk about mental illness, but it doesn't really make any sense until we talk about mental health.

ROF – So, what is your idea of health, for you?

S - For me, it's very basic stuff. Actually, there's a feeling I get in my body. It's a feeling in my belly that I know I'm well; have enough energy to do things and the thoughts in my mind aren't racing. Often, I have, like, crazy, racing thoughts, you know? So, I want a calm relationship to that, and to feel good and strong in my body. Pretty basic stuff.

ROF – What role does mentorship play in all that?

S - A key way I know I'm healthy is when I have older mentors in my life who are helping to guide me and give me feedback, and I have younger people that I'm mentoring. It recreates some kind of familial structure that I didn't have growing up. It makes me feel held in the world, in a way.

GROWING THE LENS OF ICARUS PROJECT

ROF – You've talked about how health can look different for different people. What process have you and Jacks had around making a transition into more leadership from people of color [POC] in the Icarus Project?

S – I think there's a way that it's impossible to talk about mental health or mental illness in a social and political vacuum. The things that we struggle with, we struggle with because of society. There's the internal stuff we carry around, and then the larger society places so much on us. The Icarus Project was started by two middle-class white people. Both of us had a lot of vision and drive, and inspired a lot of folks, but there are all these people who have whole sets of other experiences that we haven't had. The way that we're going to grow as an organization ….It's become really clear that the more we can bring in the voices of people who are marginalized to the center of the stage, the more that we're going to be able to be an effective movement for social change. There's this funny dance we're doing right now, where we're stepping into leadership positions, but we're also trying to step out of the ways so that others can step in.

ROF – Logistically, what does that look like for Icarus Project? As an organization founded by two white people, are you approaching folks who may be on the margins of this Icarus community with "We went you to get more involved." or are you being approached by other people? What has the process looked like?

S - We have friends who run an organization called AORTA (Anti-Oppression Resource and Training

Alliance), and our friend Leah Lakshmi [Piepzna-Samarasinha] who has a project called Mangoes With Chili. So, it's basically our friend Kiran from AORTA, and Leah Lakshmi, and me, and Jacks hanging out brainstorming what this transformation looks like. I think a lot of what it looks like is us reaching out to people who are allies, who have a connections, who are POC organizations who are doing mental health work, and asking specific people to be on an advisory board, so we bring people together and talk about what it is that we've done in the past, what they're doing, how we can collaborate and what the future might look like.

ROF - Is it a humbling process for you, as a white dude who's a founder of this group, to be examining these things and trying to step back in some ways?

S - It is by far one of the most challenging things that I've ever tried to do. And, I think often about how it's the scariest stuff that's the most rewarding.
ROF -Why is this important to you in terms of Icarus? And, how is it important to bring in a disability justice lens to the work Icarus is doing?

S – Why is it important? Imagine you're sitting at a table and you're having a conversation about mental health, and all the loudest voices having the conversation are talking about biology and genes and psych drugs. Then you look around and see there's this whole world of things that are interconnected with our mental health that have to do with oppression, and those voices aren't at the table. We are barely at the table ourselves. It's like we've been trying to do this work as a majority white organization and there are so many voices missing from our work. It's not a complete thought but I'm going to start another one…

The conclusion that I've come to after all these years of Icarus Project organizing is that race and class and gender drive people mad. The power dynamics – that's what makes people crazy! And, in some ways there's power dynamics where some people have more power than other people, but it makes people crazy all around. The oppression is there. You can feel it.

Often, as a white person I'm very conscious that there's a way to kind of check out and not have to look at oppression, as a white guy there's ways that I can check out… and I see how that makes people crazy. Why is that important? Because, I have a deep desire for people to connect with each other and build community. And there's all these ways that it's very hard for people to be able to relate each other.

ROF - So, when you talk about the privilege white people have to check out - are you saying that that makes other people crazy, like people of color, or are you also saying that it also has a negative effect on white people?

S – What I'm saying is that it has a negative effect all around! It has not just a negative effect on people of color, but it has a negative effect on the white people who are checked out, you know? So, speaking as someone who, in a process of my own relationship to my checking out, there's my own personal growth and then there's the growth of the organization that I started. And they're pretty wrapped up in each other at this point.

EMBODIED LEADERSHIP

ROF – You talk about embodied leadership - that you and Jacks have been reflecting on embodied leadership in relation to the Icarus Project. Is that tied up in some of what you were just talking about?

S – Yah. We live a culture where we are so often up in our heads we can talk and talk and talk about politics and oppression and… it's really different to make commitments to yourself about how you're going to be in the world, how you decide to be in the world, and then to be in the world; and to practice those commitments on a daily basis. So, when I say embodied leadership I am talking about a style of intentional practice.

ROF - What do you mean by that? Why is it important to have an intentional embodied practice around social justice work around mental health?

S – Because, we've been socialized to not have it; we've been socialized to not connect with each other to not connect with ourselves. It takes work to make these kind of changes. They don't happen over night, and they happen by daily repeating the same things. They also happen by getting together with other people and practicing. It's a life long process for sure.

Sascha Altman DuBrul is the co-founder of the Bay Area Seed Interchange Library, and the Icarus Project (www.theicarusproject.net), a radical community support network and media project that is actively redefining the language and culture of mental health and illness. He is the author of Maps to the Other Side: The Adventures of a Bipolar Cartographer, *a document of one person's odyssey to transform his experiences navigating the psychiatric system by building community in the face of adversity - a set of maps for how rebels and dreamers can survive and thrive in a crazy world.*



FETISH

FOR THE LOVE OF DIRT

Don't brush it off
What's dirt ever done to you?

Get down on it
Throw it round

Make a cloud
Stomp it down

Pack it into a ball
Pile it into a heap

Rinse your hair with it
For a new kinda clean

Dirt is what you make it
But I know for me
That
Dirt is best
When
Dirt is free

2012

PATTY BERNE

Patty Berne is a longtime activist, lover, and artist. She is the Director and Co-Founder of Sins Invalid, a political arts organization in California's Bay Area, and she is one of the originators of the disability justice movement. Patty and I met when I volunteered to take tickets at a Sins Invalid event in 2008. Over the years Patty has become a dear friend, both a peer and a mentor at the same time. Not only has she directed me as a performer in Sins Invalid's 2011 show, we have collaborated together artistically and politically. A lot of our friendship has been spent attending art events, eating good food, talk on the phone and catching up on what we think and feel about the world, relationships, culture and movement building. Patty is sexy and brilliant, a chef, a theatre director, a gardener and a political visionary. This interview took place in her home in Berkeley, California in March 2010, while eating banana bread and hanging out with her cat.

SINS INVALID

RING OF FIRE – What are you working on right now? What are you excited about?

PATTY – Besides improving my baking skills? Well, I think what excites me in a very, very deep way is the project I've built toward for quite a while called Sins Invalid (Sins). Its formal full name is Sins Invalid: An unashamed claim to beauty in the face of invisibility. It's a performance project that incubates and celebrates artists with disabilities, centralizing queer and gender variant artists and artists of color – all of whom have disabilities. While we are a performance project we also do political education - both internal political conversations, but also externally we do a lot of political education. For example, last year we coordinated I don't know how many sessions - I think three, at the National Gay and Lesbian task force Creating Change session. We did an all-day institute, a half-day institute and a regular workshop session. We run workshops for whomever asks.

ROF – What political work is Sins Invalid involved with?

P - Sins Invalid engages in political education like that. We helped create the disability justice track at Creating Change, we are co-coordinating the disability justice track at the Allied Media Conference, the first ever disability justice track at a national conference, with Staci Milbern, and we are speaking at a Swarthmore queer symposium and a bunch of different events and conferences that are interested in the concept of disability justice. Every three months we do a workshop that is facilitated by an artist with a disability, for anybody, to explore whatever the domain is, whatever the creative expression is. It could be poetry writing, it could be story-telling it could be movement, it could be voice. We do these workshops using different mediums, essentializing disability and sexuality is the intent.

And, we're just now starting this artist-in-residency program. The performance project this year has two programs, one is part of the National Queer Arts Festival, and then we also have our annual show, which is in October. So, that's my baby, Sins Invalid…

BEFORE SINS

ROF - Did the work you were you doing before Sins prepare you for what you are doing now?

P - I've worked in a lot of different fields. I cut my political teeth, so to speak, around the issues of US foreign policy, imperialism, and the global economic system, post-colonial economic relationships. I do a lot of work in solidarity with the Southern African liberation movements, and also did work after that in feminist organizing anti-violence, anti-rape work. I do a lot of work around the Guatemalan and Nicaraguan liberation movements, and work with what's called the

love lost movement in Haiti, which is the democratic popular movement in Haiti…

And, so I, as a person of color, a person of mixed racial descent, I am half Japanese, half Haitian, have been looking at how international resources have been appropriated by Europe and by northern countries. It has been an important part of my political development, in part because it's the framework within which I understand the world to develop. As a committed Marxist, but also as a queer disabled woman of color I need to understand that. As a way of understanding white supremacy, as a way of understanding organizing amongst communities of color, as a way of understanding how we can build a liberation movement in the United States I wanted to look at how are liberation movements in other countries developing? And I didn't want to do that just from an academic setting, you know? I mean my undergraduate degree was in Development Studies, as well as Psychology. I had a double major. And so, in Development Studies my focus was on liberation movements in Latin America. But, I mean, you know, fuck reading about it! It made sense to actually work within it.

I'm not going to center myself within oppression, I'm going to center myself within liberation.

ROF – What has your personal path looked like, as a woman of color, doing this work around disability?

P - Embodiment is huge in liberation. I feel like it's important to look at the concentric circles that happen in our development and the development of movements. I really started from the farthest circle out in some ways, right? With the material conditions of capitalism and imperialism. But, that's really important as a framework. Over time I started working amongst communities of color, and I also started working within the anti-violence movement within the us – you know the rape survivors movement, the sexual violence survivors movement, and as I've worked in kind of concentric circles I did some writing and publishing around writers of mixed descent, mixed racial descent, so these circles kept getting smaller and smaller, closer and closer to who I was as an individual. Yah, and also around queerness, the same thing. The work I did in queer LGBT (lesbian, gay, bisexual, transgender), so to speak, movement organizing was more around cultural work.

At a certain point I was working at the Center for Genetics and Society, directing a project on race, disability and eugenics. I was looking at all of the emerging reproductive and genetic technologies like pre-implantation genetic diagnosis - which basically allows a fertility doctor to look at all of the eggs that have been fertilized in a petri dish, and after extracting eggs, and fertilizing them in vitro, would look at them and say, "Well, what are the characteristics of egg a, b, c, d, e, f, g, h, I, j, k? This one looks like it may have the chromosomal structure of Downs Syndrome!" or, "Oh! The condition of Werdnig-Hoffmann Disease!" which is what I was diagnosed with. It's a neuromuscular disease; it's a type of muscular dystrophy. It's also called Spinal Muscular Atrophy type II. "And we can't have that! Not only would it make our fertility clinic have 'low success rates' but there would be more people with disabilities in the world, and we all know that is bad. We want healthy babies, we don't want crippled babies." So, y'know, some people would call that, for example me, pre-emptive genocide.

Whatever… I don't even want to talk about the genetic counseling part, because that's ridiculous. My point is that I am getting closer to the center of the circle as my work has developed, and am looking at the intersections of race, disability and life. I brought gender into it, and was actually organizing doing national organizing within the LGBT movement and also within the disability rights movement trying to raise awareness about what we're calling "techno-eugenics."

Eugenics, just to be clear, is the concept of breeding humans, so to speak, breeding out or breeding in certain characteristics. So, that includes population control, like sterilizing women that are poor, that are on public assistance, is eugenic. The sterilization of Puerto Rican women was eugenic. Hitler's programs were eugenic. The sterilization of people with disabilities is eugenic. Forced breeding of certain people within the Nazi program was eugenic. Forced breeding of enslaved Africans was eugenic. Basically, deciding who can move or who can be born and who cannot be born. And if people are interested there are some really compelling online sources on this. One that is really difficult to look at but really good is *Useless Eaters* by Dr. Mark Mostert of Rutgers University. It's a website that looks at the Third Reich of Hitler's T4 program, which was an extermination program of people with disabilities.

ROF - There's a great book that's just about that too, *Forgotten Crimes: The Holocaust and People with Disabilities* by Suzanne Evans.

P - That's the one disability advocates published! That has more stories of people from the T4 program. Oh, and there's the *War Against the Weak* by Edwin Black. There's a lot of books about this topic… So, here's the deal and thank you for saying that because this gets to the next point. Because, all I read at this place were programs like these that are attempts to kill different communities of which I am a member, queer communities, brown communities and disabled community. And then, my job was to both articulate why it's nonsense and embody why it's nonsense. Well, I don't really want to be at the crosshairs. That is not a place of power for me.

ROF - No.

P - …It was for a while. Resistance is important. And celebration is important. My life is important. If I'm going to be centered I'm not going to center myself within oppression, I'm going to center myself within liberation. And I realized at a certain point, y'know, this is ridiculous. My job cannot be a justification for why I should exist. My life's work has to be a celebration of the fact that I exist. And, that's how Sins Invalid got started.

I would say that in my personal experience, that individual, idiosyncratic, personal experience, one of the most painful elements of oppression is the negating of my sexuality, as a person with a disability.

LIBERATION EROTICS

ROF - Tell me more about how Sins got started, and specifically what brought in the erotic component?

P – Sins could have been a project on disability and beauty, or disability and cultural activism. Which, would be fine, but I've been single a lot of my life and I've been queer all my life and I've been me, whatever that is, all my life, you know? I would say that in my personal experience, that individual, idiosyncratic, personal experience, one of the most painful elements of oppression is the negating of my sexuality, as a person with a disability.

I think there is a lot of crip-centered celebratory stuff that's been developing. But, it isn't really grounded in, quite bluntly, an intersectional analysis.

Sins started because a good friend of mine, Leroy Moore and I are both hot [laughter!]… and we're both attractive and attracted to each other and we both made pornographic movies and we wanted to show them to each other. And, when we saw them we were

like, "That shit's hot! Other people should see this!" and "Wow, there are no venues for this." If we put it anywhere it would be like in its own little fucking niche. And, I don't want to do that. We need to be centered.

…And so, we were just going to show our videos at la Peña, which is a local community cultural center, invite friends and have it be low key, some popcorn… And then, there was so much attraction around the idea of it! We were pointed to the lack of one, celebration of our bodies and two, the celebration of our bodies in a political framework. I think there is a lot of crip-centered celebratory stuff that's been developing. But, it isn't really grounded in, quite bluntly, an intersectional analysis. It isn't grounded in an analysis of oppression. Those things don't often get married. I feel like people who have an analysis of oppression don't often celebrate that we're here. And, the production quality is often relatively low - which is just a comment about movement building, which is a later conversation. But, the idea that we can have both a vision and an analysis simultaneously, and that vision can be strong and beautiful and the analysis can be strong and critical, is regrettably often not there.

EMBODIMENT

ROF - One thing I've noticed from being involved in Sins Invalid is the use of the word "embodiment" a lot, by different people. It got me thinking what is that word, what does that mean? Can you talk briefly about what embodiment is to you?

P - A man named Billy Ishmael said that we are energy slowed down to the point that words become visible. Other people say that we are a spirit that is embodied in human form. Some people say that we are human beings having a spiritual experience and other people would say that we are spiritual beings having a human experience. i am more of the latter. Embodiment, to me, is essentially the integration of spiritual energy, emotional energy, intellectual energy and most powerfully, with intention for the world.

I feel very, very lucky. It is so random, my disability. It's pretty rare. And my mother is from Japan and my father is from Haiti. And it's on a recessive allele; they both had this recessive allele and met up and had a child in San Francisco, of all places, with this disability! It's quite perfect and there is clearly intention behind my existence. I am really lucky because I have seen that all my life.

I want to consciously advance, not just justice, but advance the species. Humans are amazing and we don't in any way consistently manifest our potential. I really want to see that happen. I think we're amazing; I think humans are amazing.

Everyone has a role in the universe, and I feel like mine is to manifest myself as clearly as possible and support other people in manifesting themselves as clearly as possible, in their potential for beauty and love.

ROF - On the posters for Sins it says "beauty in the face of invisibility." It doesn't say the word erotic, it doesn't say sexuality. How did you come up with language to describe the aspects of the organization that focus on sexuality?

P - The poster only has the tag line "Sins Invalid: An unashamed claim to beauty in the face of invisibility." That's really what it is, to me. People also look at our postcards, which definitely talk about sexuality, disability, embodiment and beauty, and all those phrases.

SEXUAL CURRENCY

I think we are also used to acknowledging social currency through sexuality. Let's think about the way that social culture works. People have certain amounts of currency. For instance, if a person is more fluent in pop culture, in current jokes, and has more social ease because they know either pop culture or whatever the subculture is that they are involved with, then they have more social currency. If somebody is considered media cute they have more

social currency. If somebody has the look, whatever that look is, in whatever culture or subculture they have more social currency, right? And people with disabilities are given none of that currency around sexuality. Like, we have zero dollars in terms of sex currency by the dominant culture, where the idea of disability and sexuality is so absurdly impaired that at first when we [Sins Invalid] started talking about disability and sexuality people were like what?! It was so out of left field for people that audience members brought children to the first show of Sins Invalid! [laughter] …Which was dirty, the first year was dirty. If there was a show on black gay men's sexuality there would never have been children.

We're both recognized as humans for our sexuality and dehumanized for our sexuality.

We're both recognized as humans for our sexuality and dehumanized for our sexuality. The idea of sexual rights is a fundamental part of human rights. We all have sexualities, regardless of whether or not we are in a relationship. Regardless of whether or not we are actually engaging in sex with ourselves or with someone else. We have sexual energy, sexual power, sexual identity. Those identities have rights. Those elements of our beings have rights. But again, one of the ways that we're most negated as people with disabilities and one of the ways that we're most dehumanized is by not acknowledging that we're sexual beings. So, it was both strategic in terms of politically engaging people and also, representing the deeper politics of liberation which is that we need to embody it and that it's not just "We need individual rights to go to the store" and "Civil rights are important."

I'm for being able to go to the store, and I'm for curb cuts. I'm for, you know, whatever. Being able to find a job and accessible transportation. Yes. Absolutely, without a doubt, that is the foundation. And part of that foundation is to include the right to a quality of life. And quality of life? To me, a good quality of life includes fucking. It includes being seen as somebody who fucks, and being seen as somebody that deserves pleasure. Being seen as someone who can offer pleasure. Those things are an important part of what it means to be human. If any person is kind of cast into the role of so unworthy of life, essentially, so inhumane that they aren't pleasurable to someone else, or deserving of pleasure. That's pretty low. People give that to dogs, and still don't give that to people with disabilities. That we can be pleasing and deserve to be pleased.

ROF – Tell me more about the role embodiment plays in all of this.

P - Politically, that has to be part of our means to a broader agenda of liberation, that we're seen as whole. And it's also part of our broader politic of liberation to embody that wholeness. When you embody your wholeness you're not leaving your joy at the door. I don't want to argue and justify my existence, like I've had to do in other positions, like I was referencing. I want to celebrate it, and enjoy, and be enjoyed.

I feel like Sins Invalid is a place where that can happen. Sexuality and disability are rarely paired. Sins is a way we can engage in the conversation around disability oppression and ableism that will catch peoples' attention. So, for lots of reason sexuality was essentialized.

As the concentric circles started happening, as I got closer to the center, sexuality had to be a part of it for me. I'm a survivor of sexual violence. I've dealt with a lot of medicalized violence. And I've negotiated those things largely through perverted play. And, while that may not be everybody's choice and I respect that, that has been one of my choices. I hope its not one of my only choices…

ROF - What do you mean when you say you've negotiated those things through perverted play?

P - I've played in S/M a lot. Both topping and bottoming and in a lot of different relationships of power like age play and doctor/patient stuff, and you know, just straight up power and control stuff as a way to work through having been abused.

ROF - How is that hot and empowering for you?

P - Well, originally it was because it was the best fucking sex I'd ever had!

A friend of mine was like, "Why S/M?" I started writing about the crackles of current that move through my brain and down my lips. Because of my experiences I've been hard wired that way. I couldn't help it. And rather than say I'm not going to get aroused I'm going to acknowledge what I've been hardwired to be aroused by. And do I want to just be limited to that? No, I think that through being able to play S/M, I've been able to expand my repertoire of what is arousing. Straightforward fucking is pretty hot, y'know? I'm for it. But, for a while I wasn't because I had to be a little extreme in order to get it up. And now, it's pretty fucking sexy to look in somebody's eyes. I like that. I feel like that is not just my experience. I think that's many people's experience, but it's not everyone's experience.

Ableism narrates my body to be undesirable. I have to, have to, for my life – and I mean that quite literally – in order to live I have to re-frame myself, there's no way I could live otherwise.

Sexuality is very complex. How we develop sexually that's mediated both through our individual personalities and histories, through our families, through the culture that we're in and all the systems of oppression that we're laced within. We are laced within different systems of oppression. Ableism narrates my body to be undesirable. I have to, have to, for my life – and I mean that quite literally – in order to live I have to re-frame myself, there's no way I could live otherwise. Because the framework that's put around my body says that should be ashamed to go outside. We're told a lot of horseshit. And that's not just people with disabilities, that's queer folks, gender variant folks,

Dorothy Roberts, she's brilliant, she wrote *Killing the Black Body*. She writes about the ways in which when you control sexuality and reproduction you control that community. That has happened with us. And I'm just not for it. I'm alive, so I need to live! And living means sex. [laughter] It doesn't only mean sex but it does amongst many other things it means sex. Yah… so that's part of why Sins started was the politics around it, and my individual push around it, as well. I needed it. I needed to see this in the cultural landscape around me and it wasn't there. So, yah, I helped create it.

ON DIRECTING

ROF - Can you speak to the production quality of Sins? I think that one of the things that sets Sins apart from other disability arts projects is there is such a high level of production quality.

P - Thank you. I'm just picky! [laughter] …It's true. I'm the role of the artistic director and the executive director and I'm just particular. If I'm going to do it it's going to look good.

There's a political and organizational intention behind it, too. Politically, we're competing with some intense messaging around us. If our message around disability being beautiful and natural is ableism is a system that needs to be undermined and transformed and that disability experience is part of social justice and a disability community should be integrated into social

justice movements. Those messages are not going to be heard if we look like we're a bunch of wankers.

ROF - But you are a bunch of wankers! [laughter] Are you happy with how far Sins Invalid has come?

P - Every year I see how we could do better. It's respectable. I'm getting better at it. I had no theatre experience before this.

ROF - So, in a way as you're incubating these artists to develop their work, you're also developing your own abilities.

P - Oh, absolutely. I'm totally new to being a director. And, as far as I know I'm one of the only queer, disabled woman of color who's a director in the United States.

DISABILITY JUSTICE

ROF - Tell me more about your experience in the disability rights movement.

P - I think the disability rights movement has done really great work but hasn't really looked past single-issue politics. I've heard a lot of people describe the hierarchy of oppression within disability community. "I'm the most oppressed because I'm the most disabled." Besides the fact that it's reductionistic, it's just inaccurate. It is a useless endeavor to quantify pain. Systems of oppression are more nuanced and intricate and reinforced and informed by each other than any single experience that a person could speak about. I'm not saying that people don't experience multiple layers of oppression, because people do, and at the same time that's really an argument to me to actually have a more complex analysis because we



experience multiple forms of oppression - even within disability community. So, I think the disability rights movement has done really great things on that one issue [of disability itself] and is really needing to grow. That's this idea of disability justice; understanding the disability experience, within a social justice framework

...pretty often the social justice framework doesn't look at disability. Because most people look at disability as an individual tragedy. Like, "God, it sucks to be you". A phrase that I often use is, "We may be inconvenienced by any given impairment, but what oppresses us is the systematic exclusion, and violence, and marginalization we experience because we have impairments.

ROF - What does that mean to you? For people who don't understand those words?

P - Social justice framework is a short hand way of saying that the world has been structured in a way where some people have power and privilege and other people don't, and it's based on interpersonal interactions and it's based on institutional, and systemic, system-wide forces. It's that, in general, systems are set up in this country to serve white skinned people, and to undermine the political and economic power of people of color. A white person has power over somebody of African descent in any given setting all the time. The systems in the U.S. are set up to privilege and power heterosexual people and disempower people that are gender nonconforming genderqueer, queer. How easy it if for a trans woman of color who doesn't pass to get a job at Macy's? Versus a white, think cute, non-trans woman to get a job at Macy's? The social justice framework says these are broad social forces that are bullshit. That these are systems that needs to change and there needs to be justice across all communities and within all communities.

The social justice framework typically looks at dynamics around race, particularly white supremacy and racism, around gender - meaning heteronormativity - male supremacy, patriarchy. Sometimes we'll look at class. But, pretty often the social justice framework doesn't look at disability. Because most people look at disability as an individual tragedy. Like, "God, it sucks to be you." People think of disability oppression as "Wow, it must be hard to not see. It must be hard to not walk." No, no, no. A phrase that I often use is, "We may be inconvenienced by any given impairment, but what oppresses us is the systematic exclusion, and violence, and marginalization we experience because we have impairments." That's kind of a simple way to get it.

It's real important to be crip-centered. The reality of it is it's kind of a pain in the ass to have a high maintenance body. I think that sometimes in the world of crip pride we don't want to acknowledge that. You get a lot out of it, but you pay for it too, sometimes. But, that's just reality…

ROF– It's part of the experience…

P – And, it's an important part of the experience. I wouldn't be anywhere near as developed as I am if I didn't have to suffer some. The spiritual framework says that the soil develops under the soil, or in the dark hours of the night – there are all these different metaphors for it. But really, if we have to turn private and draw from our internal resources that's where we go. If everything's easy all the time we don't always find out where our power lies.

ROF – Have you always been involved in disability activism?

Being who I am in the disability rights movement, I really wasn't seen. I grew up in San Francisco and

moved to Berkley. I went to a few disability rights movement actions in the context of the South African anti-apartheid movement and I just didn't feel like that community represented me or welcomed me. It was mostly white, a lot of queer people, but it just didn't feel like a good fit with me. It wasn't very welcoming. It's not that I'm uncomfortable around my people; it's just that their lack of awareness around the racial dynamics made me uncomfortable. I also find the disability rights movement, and again this is within the Bay Area (I can't travel very easily) has an analysis that doesn't integrate anything other than disability, so it is very single issue.

…And, I'm sure I encountered some of my own internalized ableism as well. I'm sure I did. I must've.

ROF - Like not wanting to associate with other people with disabilities?

P - No, I had friends with disabilities, lots of friends with disabilities.

ROF – So, what was the piece about internalized ableism?

P - Maybe being reluctant to challenge people around their racism in the same way that I often times do.

ROF - Because you held them under a different set of expectations?

P - I think because I have this thing around fragility. I've noticed it with my internalized sexism, too. I'm just harsher with men than with other people, partly because I'm not afraid they're going to crumble. And, I am afraid sometimes that, you know, if I'm harsh with someone, like with a woman, that she's gonna crumble. Because I do know that our ego strength is undermined in this culture. Mine is. And if mine is, then other people's must be. I'm aware of that, and I don't want to hurt anybody, y'know? So, I think it could have been that. I feel like now I can engage in critical engagement in a respectful way. Not like, "Fuck it! You're wrong!" like I might have done when I was seventeen, but with a little more nuance and intent now.

I think in the Bay Area there's entrenched leadership; they're like the old guard and they don't want to give up that power. I can understand that, and I can empathize with it.

ROF – But, do you have a critique of it at the same time?

P – All leadership transitions and has to transition. A part of the job of leadership is to know when it's no longer serving the people. I think that the leadership of the disability rights movement sees the need for itself to transform, but is lost in how to do that. In my experience it has done it more through tokenizing efforts than a really deep critique of its movement building strategies.

ROF – Specifically, do you feel like there's room for the leadership of people of color in the disability movement here?

P – Of course there is. I've been involved in different solidarity struggles, racial justice organizing, criminalization of youth, survivors of state violence, and movements have a dynamic that you can anticipate and see. The disability rights movement is kind of stuck. And that happens sometimes. Is it irritating? Fuck yah. But, it is unexpected? Is it wrong? No, it's what happens…

Think about how people who have never been listened to were able to start a movement, and right now think about how committed the leadership of that movement is to staying there. Of course, of course. And at the same time that doesn't mean that they represent all people with disabilities. The disability rights movement does not represent people with emotional disabilities, disabled people of color, it barely represents queer people with disabilities. It really does not represent poor and working class

people with disabilities. It really profoundly does not. It doesn't represent the vast majority of people with disabilities.

The disability rights movement has done great work around acquiring access through the Americans with Disabilities Act. It has done good framing work around the social model of disability, largely articulated now through the Disability Studies work. It has created an infrastructure for independent living. I think those are all really big gains. And, I think at the same time those gains don't represent what would necessarily be the highest political priorities for all people with disabilities.

…the second wave of disability rights we're calling disability justice. And that includes disability rights, but it centers queer folks with disabilities and disabled people of color.

ROF – Do you see Sins as being part of the disability rights movement?

P – Sins Invalid is not in any way a part of the disability rights movement. Sins has a relationship to disability community. I think that we're building on many of the gains of the disability rights movement. We are not born from the disability rights movement. I don't see us as working within the disability rights movement. We barely work within disability culture. No.

For me a movement building strategy is to acknowledge the work of a movement. We don't have to be in the disability rights movement and deconstruct it. We just build something bigger that encompasses it and it can dissolve into that. There is necessarily a first wave of everything, so the second wave of disability rights we're calling disability justice. And that includes disability rights, but it centers queer folks with disabilities and disabled people of color. It includes those access claims and rights, but expands past that to collective claims for communities, not just individuals, and has an analysis around the ways that white supremacy interacts with ableism. Disability justice has an understanding of the ways we need to be allies as people with disabilities with native people that are asserting sovereignty. In a second wave of disability like disability justice, there are very strong clear alliances between trans and gender variant folks and people with disabilities. There are very natural alliances and we can really build from those natural alliances.

I really appreciate the work people have done. It's important. Without the first wave there is no second wave.

DISABILITY CULTURE

ROF – That's fascinating to me, because I think Sins Invalid is helping to grow disability culture, and is disability culture in action.

P – Yes! It is. It is.

No, we didn't come out of disability culture. We came out of the social justice left. Completely out of the social justice left. We are people of color, queer folks. Disability culture doesn't fucking reflect us. We are not like, "Hi, I'm proud and disabled." I mean that's a given. That's a given. There has to be vision. And the disability rights movement, the vision that it built, needs to be expanded. The work that Sins is doing is situating itself within an expanded vision. It's in reference to a vision that includes all communities. People of color, queer folks, gender variant folks, people with disabilities. Because we're all of those things. Sins is really at those intersections.

We don't come out of disability culture any more than we come out of queer culture. We're probably closer to coming out of queer culture, quite honestly. Like, look at Eli Clare's work, right? Is he from disability culture? Is he from queer culture? Where is he situated? It can't be separated. His work may

have informed my thinking, but where did his work come from? Do I see us as a lineage within disability culture? No. We are building it forward. Do I see us as emerging from that lineage? No.

There was an organization called Luna Sea Productions, Veronica Combs was the choreographer; it was a queer women's cultural space in San Francisco. She did this thing called Liquid Fire Productions that was all queer women of color. I see us in that lineage. I see us in the lineage of Brush Me Productions – a queer gender variant production. It's hot as fuck, run by Sean Dorsey [Bay Area choreographer]. I see us in the lineage of Essex Hemphill and Marlon Riggs who were queer black men who wrote about their experience at multiple intersections... I see us in all those lineages.

Patty Berne is a Co-Founder and Director of Sins Invalid, a disability justice based performance project on embodiment, disability and sexuality. Hailing from San Francisco CA, Patty's background includes advocacy for immigrants who seek asylum due to war and torture; community organizing within the Haitian diaspora; international support work for the Guatemalan democratic movement; work with incarcerated youth toward alternatives to the criminal legal system; advocating for LGBTQI community and disability rights perspectives within the field of reproductive and genetic technologies; offering mental health support to survivors of violence; and cultural activism to centralize marginalized voices, particularly those of people with disabilities. Patty's training in psychology focused on trauma and healing for survivors of interpersonal and state-sponsored violence. Her work can be seen at http://www.sinsinvalid.org/.

I WONDER IF THE SMILE HELPS

I wonder if the smile helps
When I say the words
Your insurance won't pay for this

Whether it does or not
I can tell you thought I was nice
But in the end
It doesn't really matter

Since who will do your dishes
And how will you get to the grocery store
Without the wheelchair I would have ordered for you
Had your insurance paid for it

2010



TELL ME WHAT YOU WANT

LEAH LAKSHMI PIEPZNA-SAMARASINHA

I met Leah Lakshmi Piepzna-Samarasinha in 2008 at a San Francisco taqueria after a performance by Sins Invalid, a Bay Area disability and political arts organization. I was immediately struck by several things, namely her quick sense of humor, her love of excellent food, the rapid pace at which she speaks, and her glamorous wardrobe filled with many gem tones. Since that time we have become friends and artistic collaborators. Leah is a well-known writer, speaker, and community leader who became chronically ill in 1997 and was eventually diagnosed with Fibromyalgia. In 2006 she co-founded a literary organization called Mangoes With Chili with Cherry Galette, which features the work of queer and trans writers of color. One night in the Summer of 2013 Leah was at a writing residency in the California Redwoods, and I interviewed her over the phone from my home in Seattle about what it's like to be a disabled touring performer, and how race, class, and femmeness influenced her process of claiming disability.

HER ENTRY POINT

RING OF FIRE – Leah, the first thing you said you wanted to talk about was the event that Loree Erickson [Loree is a porn maker and academic who lives between Canada and the USA] put on in 2007…

LEAH - That event was my entry point into seeing how I could be a disabled performer who brought disability into a performance space. Loree asked me to perform at this event in Toronto. It was right before I left Toronto to move to Oakland for grad school. I don't remember the name of the event, but basically when Loree talked to me about the event she was like "Yah, it's about sex and disability" with disabled queer performers. At the time I had been chronically ill for ten years but I was really, really tentative about having a politicized ability identity. That can be a very typical thing for a lot of people who have chronic illnesses who have acquired them later in life, where we're very much living a disabled existence, but kind of like *Oh, do I get to identify as disabled?, Do I have a quote unquote invisible disability?,* all that stuff. But, I was really excited that she asked me. Loree's porn film "Want" was the only thing I'd seen that was by someone my age and about disability and sexuality and queerness and desirability.

I went home and I wrote this whole piece about having Fibromyalgia and I wrote about a lot of things that were really, really challenging for me, in terms of having Fibromyalgia and trying to be sexual. And, it was a good piece. It was an honest piece. …But, it was a really fucking downer piece! It was very much like, "Fibromyalgia is appalling! Fibromyalgia is terrible!" It was very much "I hate my body," y'know? I kind of thought the whole show was going to be like that. And, I show up to the show, and my mind just got blown because there's all these different performers and they're not all being like "Oh, I'm disabled and my life sucks and woe is me and this is terrible and no one will want to date me." They were reading porn and talking about being slutty. One of the things I always remember, that really was one of my gateways into disability and queer consciousness, was this piece AJ Withers [AJ is a Canadian artist and academic] did where they performed a choose-your-own-adventure story. The premise was there were four queer crips, they were locked in a house together having an orgy, and then the zombie apocalypse starts! [laughter]

ROF - Amazing!

L - I know!!! There was somebody fucking somebody with a cane. There was somebody who had a dildo strapped onto a wheelchair. And, it was like all this cross disability stuff and multiple genders represented and it was like a choose-your-own-adventure, so it was like "If you want to crew to try to go to the bathhouse for help turn to page 36. If you want them to fuck their way out of being attacked by

zombies turn to page 38. And, AJ had written all this stuff around not leaving anyone behind, like there's one scene where there's a truck that can only take three people, but they're a group of four and it's not accessible for one of them, so they all stick together. And it was really sexy. I left the show with my *jaw hanging open.*

I had never thought of disability that way – that it doesn't have to be tragic; it doesn't have to be sad. Y'know, that can be part of it, but it was just that kind of consciousness raising 101 experience that so many crips have, of realizing that disability doesn't have to be this individual tragedy to your body, but that disabled people are part of a community, disabled people have a history, disabled people have all kinds of ways of having sex, and we can work together and do things and it can be really fun. And some of the things that are hard aren't because my body is a liability, they're because of ableism. So, I did the thing where I rewrote my piece while sitting right there in the fucking audience. Like, I stood up there reading something where everything was crossed out. [laughter]

... disabled people are part of a community, disabled people have all kinds of ways of having sex, and we can work together and do things and it can be really fun. And some of the things that are hard aren't because my body is a liability, they're because of ableism.

I can't hand it to crips in Toronto enough for organizing those kinds of events year after year after year.

SINS INVALID

ROF - Leah, tell me about how performing with Sins Invalid (Sins) changed your ideas about what was possible as a disabled artist?

L - Well, I got asked to perform with Sins in 2009. At that point I'd been back in the States for two years and I'd been touring with Mangoes With Chili (Mangoes) a lot. At that point we'd gone on two North American tours and I was traveling a lot more and performing a lot more.

For me, as someone with a chronic illness where my energy goes up and down, touring was the way I figured out that I could make money. The way I had figured it out in my head was there's no way I can work a 9 to 5 full time job because I'm too sick, but what I can do is kind of save up my energy and organize these college gigs, where I go and I perform and I do workshops, and I get well paid. And then, I come back and usually crash and have to recover for a couple of weeks. So, I was very proud of myself for figuring out the solution.

But, at the same time, I was not in a space where I knew that I could ask people who were bringing me in "Hey I need a space that doesn't have a lot of stairs, and I need not a lot of cigarette smoke, and I need to get food, and stuff like that." I did not feel comfortable asking for any access needs - I just thought they wouldn't book me if I did. Like so many different kinds of crips, the idea of even asking for those accommodations feels huge and impossible. Because asking for accommodations gets so not normalized by society, because of the ways that disability is invisibilized.

So, when I was working with Sins, when it really hit me how different it was, was when I was informed by Patty or Leroy, or both, [Patty Berne and Leroy Moore are the founders of Sins Invalid] that leading up to the performance we were going to have a whole tech week. I had never been in any kind of performance, in ten years of performing, where we had a whole week to rehearse. That was the first thing that kind of blew my mind. There are so many marginalized artists who have that model of performing where you're lucky if you get to show up to the theatre an hour before,

and most theatres work that way. And, of course, if you're disabled that doesn't give a lot of room for times when you accessible van was late, or you got sick, or you threw up on the subway, or y'know, all of those things.

When I got to the theatre, one of the first things we did was we were all in the green room together, all the people who were going to be in the show. And y'know, we were very cross disabled. There was Aurora Levins Morales, who has multiple chemical sensitivity and other disabilities, Antoine Hunter who's a Deaf dancer, Mat Fraser from the UK who has short arms and is bodily different. There were so many different kinds of crips! Patty said that the first thing we did was we were all going to go around in a circle and we were each going to say what our access needs were for the week. I had never experienced that before. I had *definitely* never experienced that we had two hours to go around and say, in detail, what it was we needed to be in the space. And, like a lot of people who are doing an access check in for the first time, I was like *I am not allowed to really bring my whole body into the room. I just have to pretend that I'm able-bodied like everybody else*, so my first check in was really tentative. And someone else said, "I need a chair." and I was like "Oh right, I need that too, I just always forget to talk about it."

So, that was the way Sins was structurally set up from the beginning, to really center our body's needs and our disabled bodies, period, instead of our disabled bodies being a complete, total after thought. It meant so much. And, it really sent a message that our disabled bodies being able to show up fully was part of what made the performance happen, in the way that everyone at Sins wanted it to happen. It blew my mind.



And, it also blew my mind when we worked out solutions for when people's access needs are contradictory. For example, one year there was somebody who was like, "Y'know the temperature has to be below 70 degrees or my body won't work." and somebody else was like, "I need it over 90," and y'know, we worked it out. We hung out in separate areas and we used a space heater in one area and a fan in the other. That that was thought about. There was really good food available for us, and I felt comfortable taking all the space I needed to warm up and do yoga and stretch. You could cry if you needed to. All that space was there. It made for a performance where afterwards everyone in the audience who knew me was like, "This was the best performance I've ever seen you do. You were so present, you were so slowed down." I remember thinking *I don't know how to explain this to some people*, like *I don't know if they'll get it.* The reason why I was able to be so 100% present on stage was because of that access, and just the way they had done it.

TOURING AS A PERFOMER WITH CHRONIC ILLNESS

ROF – Can you talk about how being in Sins Invalid changed the way you've performed since then?

L – Well, in terms of being a touring performer, even with touring organizations who are doing things on a social justice framework, it's not like "No, we're not going to do access." they just don't necessarily centralize it. Even in Mangoes we definitely didn't always centralize it. In our second North American tour we had one performer with Fibromyalgia and MCS (Multiple Chemical Sensitivities) and a lot of stuff. We asked hir if ze wanted to go on tour and ze was like "I totally want to, but if I'm going to be in van it must be scent-free." And, I remember being like "totally" and then, like a lot of people who are early in the scent-free curve thing, *Shit, do I know how to do that? Shit, I don't even know if I can promise that. We can't really ensure that some people can do it.* I mean a lot of people don't know how to do it. Some performers that wear costumes have used a lot of scented body products, and those scents are just in there. But, we did work to make it scent-free. It definitely wasn't100%, but it was a beginning of *Oh yah, disability*. Y'know?

And, so for me, one thing that happened going on tour right after Sins – and I heard a number of people who also did Sins and afterwards went on non-disabled tours were like "Oh wow, I've been spoiled." I didn't want to go back to the way it was before. To where it is so assumed that everybody is able-bodied, and there's no centralization of access, no normalization of access. Y'know, the standard mythology around touring is that it's really rugged. You get up every day and get in the van and you don't really sleep. It's a different city every night. The tour I went on right after Sins was really hard. My body was so worn out and I was just really, really conscious of the ways in which I just completely accepted *Touring is just going to destroy me and I'm just going to suck it up because that's just how it is*. With this tour I was like, *I don't even know what the answer is. I don't even know if touring can be sustainable when you do it for three weeks*. I am really clear that I need to plan it differently, especially as I get older.

My friend once said that you've got to be really fucking tough to let people see you not being so tough all the time.

So, out of that, I think for me, as somebody who's a producer and a performer, came a lot of things. Some of the process about tour, talking about all this stuff with other performers, really working towards trying to centralize access, and teach about the things I learned from *Sins* into other performances that I curate or produce. Centering a lot of education. There are a lot of queer, people of color, social-justice oriented performers who, because we're not separate from the ways that mainstream culture is fucked up,

had not really thought about ableism before beyond "Oh, ramps" and that very basic kind of 101 access.

So, that's been a really interesting process. Both having experiences where people come out to you about being disabled, who've never felt like they could talk about it before, and that being amazing, and work. And also, bumping up into the grief of what happens when - for me it's been a really hard thing, as someone who works within queer, POC (people of color), cultural, political communities here and was kind of closeted about being disabled - I got to the point where I was like I*'m not willing to just have my crip life in one corner, and then be in hip hop world, and try to be as non-apparent as possible*. I want to be able to have everybody get this and to really see the resistance, the denial, the forgetting, and the ableism that's heartbreaking for me, and a lot of other people. Yah.

CENTRALIZING DISABILITY AND DEAFNESS

ROF – What are you excited about now?

L - One thing that I'm really excited about is that out of the hard times and grief around feeling hurt that all these non-disabled queer, POC, artists don't get it, or care to get it, about disability, what I have seen coming up more and more over the last three years, is that there's a lot more centralizing of disability issues in a lot of different performance spaces.

We've got a huge long way to go, but I've got to say Toronto has had, for a long time, a really amazing disability and psychiatric survivor community that is very queer and sometimes very POC, and it has done a lot of organizing. This stuff started happening a couple years ago, out of different crips' efforts, where people just started being like, "No, it's not ok to have your event in a non-accessible space." Not like, "Oh, but it's a really cute space", or "Oh, we couldn't find anyplace else." No. more like "We've made this Google spread sheet of every single space in Toronto that is accessible and what kind of access it is and how expensive it is." It was crips, a lot of cross-disabled queer crips, and also a lot of allies who made that happen.

Elisha Lim, who's a non-disabled, trans, queer artist of color started a Facebook event called ""Why would I go to a party my friends can't go to?" where they were like, "I don't want to go to any events that are at a non-accessible space and I'm going to talk about it." They had seen what a lot of disabled folks have had to do when there are non-accessible events, like calling people out and then being told "Oh, we didn't know." or "It was too hard." And Elisha was just like "No, we're just going to push harder."

I mean, maybe it's the bubble that I hang out in, in Toronto, but it's a pretty big bubble…

And y'know, it's been really beautiful to go to events in Toronto that are wheelchair accessible, including the bathrooms, and it's an inclusive space. And, there been a lot of really amazing deaf queer organizing. I've had to learn a lot about my own audism. There's been a lot of work a lot of people have done and it's resulted in the fact that you can go to a lot of events, where there's a whole bunch of people who are Deaf and hard of hearing who are in the front row. It's a lot of Deaf people now at events, and people have become really proactive about how to fundraise for ASL interpreters. It's got to the point where, when I tried to get ASL interpreters for a Mangoes show happening in Toronto in April I started two months out to book, and I had a really hard time finding an interpreter because the demand was so high. It's just skyrocketed in the past couple years.

Um, so yah, just having performance spaces where there's parents who are able to go because there's childcare, where there's ASL, where there is a scent-free space there, where people are really conscious about making space where people can sit, and where some of these events end earlier. It just seems like there's a beautiful community that is cross-disabled, and that also looks at parenting and being old and all the kinds of ways that access is thought about,

it's just really, really exciting to me. And I really feel like there are a lot of people to witness it. It's slower in Oakland. I don't necessarily see that every queer event is like that. It still feels pretty able-bodied. But, I do see through the work of a lot of people, there being more centralization of disability stuff and more people who are willing to listen and to put themselves out there. And, I just hope we can keep building that, it would be nice for things to keep getting less fucked up than more fucked up.

ROF - Well, that's ending on a very positive note! [laughter]

L- Thanks, I tried! [laughter]

WORKING CLASS FEMME OF COLOR

ROF - Did you want to say anything more about being a working class femme and your disability?

L - For me, one thing that made it really difficult to a claim a disabled identity for a long time wasn't just – well, a lot of it was the whiteness of the mainstream disability rights movement - but it was also a lot around class. I think that for me, as a person who's chronically ill and the daughter of a working class white woman - who has polio actually, but she never identified as disabled - there was just like a certain feeling for me and a lot of folks I knew. I didn't feel like disability was a middle class thing, but I did feel like I did not stand to gain a lot by claiming "disabled" as a label. I felt like, in order to survive, in order to economically or socially survive, I just had to be very tough, and very capable, and very self-sufficient, and very indestructible. And, y'know, it's complicated, especially since working class is such a complicated thing, and there's a lot of working class values that actually really value interdependence and community.

Sometimes in my own family a lot of what my mom talked about was "You have to take care of yourself. You can't trust other people. You definitely can't talk to social services." I remember at some point I was super convinced my mom should take us to family counseling. And, she just was like, "Why would you want to go there? Do you want social services to take you away?" She was speaking from her own completely legitimate lived experience, which was not as someone middle or upper middle class who goes to see a therapist.

For me, a lot of the way that class crossed over into my experience of femmeness, was later on in my life, where a lot of the communities I was in were pretty femmephobic. I felt like the way that I could be someone who was femme in a way that was valued was to have a femmeness that was very tough, and very kick-down-the-door, y'know, very hard femme in the way of being regarded as tough, and confident, and dependable, and never really vulnerable. To me, that's very much about race and class.

So, it was really tricky. One of the trickiest things about coming out as disabled was about being able to come from a place I could ask myself "What would it be like to ask for help?" Is it possible for me to have a working and mixed class femme of color gender, that is tough and strong and all of those things, but also be able to say, "Hey, I'm actually not physically strong right now. I'm actually feeling pretty weak," and that doesn't mean that I'm not valuable. Does that make sense?

I think that it's really amazing to see the ways in which queer femmes of any gender, who are disabled, redefining the ways in which strength and softness work in our bodies.

ROF - Totally. I think a lot of people think that by saying you can't do something you are saying you're

weak and that brings up feelings, because they think that's a bad thing. And, also it's hard to make yourself that vulnerable.

L – Yah, and I think specifically around femmeness, most of the culture around femininity is so hated, and is seen as weak in a bad way. Y'know, "pussy" is an insult that's all about weakness, right?

My friend once said that you've got to be really fucking tough to let people see you not being so tough all the time. I think, as somebody who's feminine at center, who has chosen to define that as a source of strength in the face of this culture, in can be really difficult to come from the place my friend talks about. And that's kind of the paradox of it, y'know?

There's a lot of ways in which femmephobia and disability are intertwined because of the ways in which ableism plays out. I've met crips of a lot of different kinds of genders, and people will say, "Oh yah, disability feminizes you. You're not seen as tough. You're not seen as strong." And, I think that there's actually a lot of subconscious disability activist culture that could be seen as kind of a pushing back against that, being like "No! We're tough! No! We're hard!" It's really complicated. I don't mean to pathologize everybody who does wheelchair rugby and shit like that. But, I do think sometimes people really have a need to be like, "I don't want to be that feminine soft thing. I want to be tough and strong and hard, because I have a body that's really porous or vulnerable or different." And, I think that it's really amazing to see the ways in which queer femmes of any gender, who are disabled, redefining the ways in which strength and softness works in our bodies.

That's a good place to end!

ROF – Well, Leah, that's awesome. Thank you.

Leah Lakshmi Piepzna-Samarasinha is a queer disabled Sri Lankan cis femme writer, performer, organizer and badass visionary healer. The author of the Lambda Award winning Love Cake *and* Consensual Genocide *and co-editor of* The Revolution Starts At Home: Confronting Intimate Violence in Activist Communities*, she is the co-founder of Mangos With Chili and a lead artist with Sins Invalid. In 2010 she was named one of the Feminist Press' "40 Feminists Under 40 Who Are Shaping the Future" and she is one of the 2013 Autostraddle Alternative Hot 105. Her website is brownstargirl.org.*

THE DAUGHTER SHE NEVER HAD

BY ELLERY RUSSIAN 2008

WHEN MY MOM HAD HER MIDLIFE CRISIS I WAS THIRTEEN.

SHE STARTED GOING TO PSYCHIC FAIRS.

PSY CHIC FAIR

SHE SAW SOMEONE WHO TALKED TO PEOPLE ON "THE OTHER SIDE".

Lois

Hazel

MY GRANDMA LOIS HAD AN OLDER SISTER HAZEL WHO DIED YOUNG

THEY WERE RAISED CHRISTIAN SCIENTIST AND DID NOT GO TO THE DOCTOR.

Greenwood Memorial Terrace

SPOKANE WASHINGTON

HAZEL HAD DIABETES, WHICH SHE DID NOT MANAGE MEDICALLY. SHE DIED OF COMPLICATIONS WITH PNEUMONIA IN HER FORTIES.

SHE WAS MARRIED TWICE, BUT HAD NO KIDS.

THE PSYCHIC TOLD MY MOM THAT I WAS THE DAUGHTER SHE WOULD HAVE HAD - IF SHE LIVED.

APPARENTLY, HAZEL "CHOSE" MY MOM TO HAVE ME.

I SOON DEVELOPED A FASCINATION WITH HAZEL. MY GRANDMA INDULGED ME BY WRITING A SHORT BIOGRAPHY OF HER SISTER.

As a pre-teen, I'm sure I gave Hazel problems. I'm sure that on more than one occasion/she sought help from her Sunday School teacher about how to deal with me



YULIA ARAKELYAN AND ERIK FERGUSON

I met Erik Ferguson and Yulia Arakelyan years ago at a dance workshop in Washington State taught by the Seattle dance company Light Motion. Erik and Yulia are both dancers and choreographers, and together their dance company is called Wobbly. In Winter 2010 I met them in what was, at the time, their new dance studio at an artist space in Portland called Zoom Studios. We discussed the importance of accessible venues for the creation of art, what dance forms they are excited about, and why they are moving away from dance community that are specifically focused on disability dance. Even though Erik and Yulia are no longer at Zoom studios since the time this interview was conducted, the themes of this conversation still feel relevant.

WOBBLY DANCE

RING OF FIRE - Could you start with just talking about who you are and about your space?

YULIA - Well, together we call ourselves Wobbly or Wobbly Dance Arts. We don't just do dance, Erik does visual art and sculpture stuff as well.

ERIK - And you're rocking the dance film... We're a group together. We are wobbly together and it's embedded in our relationship. We are artistic partners.

Y - Where should I start? …Well, we just moved in really, we are just starting to build it out and it's a fairly small space. But, it's mainly like a house for our creative space, where we can just be ourselves and make art and have small rehearsals. It's not a huge space to dance in. We've got 250 sq feet - less than that, 236 - with which to try to both make visual art and be physically present and dance and stretch.

E - I've used the word oasis.

ROF - When did you move in?

Y - Well, January, but it took us a really long time to actually start painting and moving our supplies. The reason for that is we only have help at certain times of the week and certain times of the day, so coordinating that…

E - I've been in eating disorder rehab for the past 40 days. I just got out today, I graduated today. And I contemplated whether or not to even bring that up, but it plays into the timeline and it plays into where I'm at with my own body. A lot of the focus shifted to my health and getting me into treatment, and basically I've been in treatment 9 to 5 every day except weekends for the past 40 days.

Y - …So yah, personal life, interpersonal stuff… A lot of our energy in the past two months has been on that. We're just starting to build our oasis. We're going to get a lot of plants in here. And a marley floor, eventually. It's kind of a dancer's version of linoleum.

ZOOMTOPIA

ROF - Could you talk a little bit about Zoomtopia as a project, and why you're excited about it?

Y - Zoomtopia is Carole Zoom's vision.

Y - She's an artist and a disability activist, well activist on just anything.

E - She bought a building in Eugene, Oregon and opened it up to liberal arts groups, and then turned it over to the tenants. So, it's basically a rent-to-own thing. And, she wanted to do it here in Portland, so this is her second one.

Y - Her vision is really to build this space for artists, and in a couple of years have the option of the tenants buying the building from her, basically. Her other vision is making the space totally accessible, universal design throughout.

CREATING ACCESSIBLE A TRULY ART SPACE

ROF - How has that affected you?

E - We wouldn't be here. We would not be here, if it wasn't for the devotion to total accessibility. Like, not only the fact that it's quote unquote ADA compliant, because that's accessibility 101. There's so much more to it than that, and she knows that.

Y – Like the six wheelchair accessible stalls, and the roll in shower.

E – Even to the extent that right now, the single room bathroom has to legally have a man and woman's symbol on that. But, she said "Come up with something, and fuck it up and put it over it, under it, do something else to it, so it's accessible queer-wise and disability-wise." And she felt really committed that I want people with disabilities, specifically I want the two of you in this building at it's base. She wouldn't feel right if the whole building, when it was said and done, had no tenants with disabilities.

Y - We had been working with her before she even started building this space… We came in and she worked with us and said "How much can you afford each month? Like, what square footage do you want and how much can you afford?" And, this is the only studio this size. Everything else is like 900-1,000 square foot. So, she built this for us, basically.



And, we looked at other spaces – like, I don't know if Seattle has it – but it's called Active Space, which are pretty cheap studios. But, it's not the same, the focus isn't on accessibility or community. We would've just been renting a studio in a building and have to fight to make things accessible. Whereas, here it's like…

E - Here you don't have to go back again and again. Like, Yulia's requirements for an accessible toilet are incredibly specific to her. The ADA measurements do not work for her. And she has to go back again and again saying "I'm sorry, it's still not working. It needs to be one inch lower." Whereas, in another space that's really embaressing.

Y – With Carole there is anything that I can tell her and I know that she would understand.

ROF - What is it about Carole that creates that feeling for you?

E – Well, she's one of us. She's also somebody who has a great deal of power in the community. She is a force in the arts community at large. So, it's the combination of the fact that she's a person with a disability, plus she has this reputation and this force in the arts community and, you know, she happens to have money.

ROF - It sounds like she's also committed to making things truly accessible, not just ADA accessible, like the minimum required by the law, but actually going the full measure to make things truly accessible for real artists.

It's so inspiring to be part of a community... because being a successful artist almost never happens in isolation.

Y - Yah, totally. You know it's funny… she had to work with the contractors. There was such a divide between what she asked and what their idea of accessible was. Like, the alarm system, the light switches and the hooks in the bathroom, they were all high, even the push buttons for the doorways. Like, they just didn't have the idea that "Hey Carole can't reach that." even though they know her personally. The contractors. So, after everything was built she had to go back and tell them "That's too high."

ROF - How does being here make you feel creatively?

Y – Lots of things. The first thing that comes to mind is that there are so many different kinds of artists here. There's a photographer, a glass blower, writers, dancers, jewelry designers, painters. And just being part of that and feeding off of each other's ideas and artistic creations and vision, that's really inspiring.

E – It's so inspiring to be part of a community of people, because being a successful artist almost never happens in isolation. The real true reality of being an artist and being successful does not look like that. To make the connections, you have to be able to make the connections. And as a multi-disciplinary artist - I think both of us are multi-disciplinary artists - I am just, like, drooling with excitement over the fact I could write, I could dance, I could paint, we could make film, we could make experimental music, just name a discipline, we could have it here. And we could have not just the discipline itself, but the connections to go somewhere with it. It's just phenomenal, head over heels incredible.

Y - And we're going to be - the whole building is going to be - part of the first Friday Art Walks. So, having that opportunity to show our work, paintings, drawings, dance installations… That's our idea for the space, to use it as, yes, a creative working space and open it up for art showings and installations, dance installations, and movement installations.

ROF – Did Carole fund the project personally to get it started up or did she do grant writing?

E – She sunk over a million, over two million into this program. As far as I know, there's no grant involved.

DANCE COMMUNITY

ROF - What are you guys working on creatively right now? And what are you are excited about?

E – The last two years Wobbly has kind of been this idea that's forming around the two of us, dancing butoh. It's really heavily about butoh. But then also, my visual art is kind of coming out of the woodwork. Showing a few of those prints at the Disability Art and Culture Project two years ago and people saying "I had no idea that you did this." And people saying, "Oh, I thought your performance at such and such was cute, but this is really good." It made me realize that I have a ton of stuff in storage that I have kind of put to sleep because I was working visual art in isolation and it was my connections with the contact improvisation community that was making my life change and move and things were growing from that. I also have been processing through an extreme amount of self-hatred about my physicality and about how I feel as a spastic dancer as opposed to a dancer with another type of disability. And how I feel that that body type is underrepresented in the dance world and I wasn't seeing myself and I just kind of turned that into a kind of internal ugliness and stuff. I also had major surgery on my bladder two years ago which was for the good but I think it really kind of took me out of commission and deconditioned me as far as dancing was concerned. On the whole a lot of different things happened, so I really had stopped dancing and probably would have dropped out of the dance community all together were it not for the fact that I'm married to Yulia, who is this trained dancer and still very much invested and being fed by dance.
Y – I would drag him to every dance show I went to.

ROF – Why?

Y – Because I wanted him to go. I didn't want to go alone. And, I knew it was good for Erik. I was like, "You are not dropping out of the dance community."

E – It was good for me. But, I also think that so much of the beginning of our love affair was based on the fact that we are both dancers. And, I think the idea that I might stop being a dancer was really kind of threatening to our identity as a couple. ...And then, we did a performance.

Y – Our Wobbly debut. It was last Summer, at the Water In the Desert Butoh Festival. It was a butoh festival put on by Mizu Desierto.

E – It made such a difference for me because we were invited and I stopped feeling like I had something to prove. Almost all the other stuff I did I constantly felt like I had to carve out a space for myself with the contact dance, carve out a space for myself at various dance festivals, various dance classes. For a while I had the energy and excitement to do that, and then I just couldn't. Knowing that Mizu invited us, knowing that she wanted what we had, and that she wanted us as we were, that she was willing to work with that, just opened me, opened us both.

BUTOH

ROF – It seems like you guys are getting involved with this butoh community and I wonder what has been the draw for you guys toward that community and how you feel about that.

Y – I think separately before we even met we were drawn to this art form, butoh. So, we're individually drawn to it and it's a dance form that I think, for me, allows us to be our crippled selves and it kind of …I'm always at a loss for words describing what butoh is. In butoh imperfections are beautiful. … for me, that's the attraction of this dance form. I can be myself. I don't have to worry about lines and fitting into a certain mold like modern dance or ballet. In Seattle there was some strong butoh community and then when I moved to Portland my first class here that I found was with Mizu and that's how I started working with her.

ROF – I know that you've also done some contact improvisation.

Y – I think Erik has done more contact than me and is more into it. I started dancing out and through contact, by going to jams. But, at a certain point, and I don't know when that happened, I didn't feel comfortable or safe in that environment. It had to do with having a couple of bad experiences at a jam. So, I just sort of dropped out.

ROF - What were your bad experiences?

Y – I was always the only one in a wheelchair. A lot of contact improvisation is listening to each other, right? But, there were just a few experiences where someone tried to lift me and it was not okay or safe, and the jams that I was going to there was a lot of lifting and going up into the air. That's not the kind of dancing or space that I want to be in. So, having a few bad experiences like that I think I just decided I don't want to deal with that.

ROF - Why butoh? Has it felt different for you than other dance forms?

Y - Oh, totally. A lot of times in butoh the focus is on transformation and personal transformation, working individually, I think.

E – Yah, there's a lot more individual work. Whereas contact improvisation, by definition, is almost always a partner practice and dancers are often even lined up and matched with each other according to size, according to height.
Y – With butoh, yes it's really physical, my body will get tired, it's intense. But, the focus is more based on visions, internal work, and pushing yourself to explore imagery-based work, so it's up to you to find. One thing that we did with Mizu was the bite of death or the bite of poison. We had to bite each other and it was like poison going through.

E – Not like physically sinking your teeth.

Y – But, more like energetically.

E – Like, you wouldn't make the mime that you were going to.

Y – Some people did a little bit, but it was the vision in finding what that meant in your body, like having poison going through you and finding that dance. So it's not like someone telling you you're going to thrash around on the ground. That might be your dance or it might be something completely different in your experience of it and your exploration of whatever image or vision.

ROF – Are you two dancing in your chairs mostly, with the butoh work?

E - The piece that we did in June, we were not in our wheelchairs at all.

Y – We started out in office chairs on wheels. We had two people, well one person behind us, each, wearing all black, so it's as a quartet, but they were like part of us. We weren't separate.

E - They were hidden for the first part of the performance, so it looked like we were moving in these office chairs, unbidden. Part of that image came from this idea of "How do you get help on stage to do things that you might not be able to do by yourself, but not have it be like you are just being pushed or aided?" It's sort of this idea of puppeteers that you can see, they're not hidden. It's made obvious through the convention, like they're completely in black, maybe even their faces are even screened in black, so you know that they're there, but you realize it's not part of the show.

Y – Although they were. They were a big part of it. That was the first part with the chairs and then they helped us get down on the floor and they rolled the chairs away and the second part was on the floor.

CRAVING SOMETHING BROADER

ROF – I remember when I saw you last Erik, you were talking about your burnout with disability performance versus just general performance, and kind of the difference between the two. You were doing the Disability Arts and Culture Project and now you have the studio, and you are doing the Wobbly work together. You are kind of going in a new direction, where do you see that going?

E – I think there's definitely a craving to not be pigeonholed into disability art. And it's not because there's anything wrong with disability art. It's just sort of out of a frustration of like, you know some people would say that because we are who we are, whatever we do is disability art and that makes me want to throw up. And, so I think that there's definitely a desire to move into something broader, something that is not so easily categorized.

Y – I think that was our idea behind the dance piece – that we did for last Summer. Of course people that knew us knew we are wheelchair users and disabled. But largely we wanted to not have that be the focus and that's why our idea with the office chairs…

ROF – It presents a very different kind of symbolic image.

Y – Yah, not hiding our disabilities, cuz that's kind of impossible! [laughter]

E – Well, you can't! [laughter] I mean there was in the beginning this sort of little trick about hiding how we were moved, in a way, but then in the end, you know, we were very much expressing ourselves with our bodies, the way that we are. I even had movement sequences that were built around the fact that I am really good at crawling around on the floor, and that I can turn my thumbs around backwards. And we had people mimicking me, crawling in the way that I crawl, and moving my hands the way that I move my hands and turning my thumbs around backwards. So,

> ***…some people would say that because we are who we are, whatever we do is disability art and that makes me want to throw up. And, so I think that there's definitely a desire to move into something broader, something that is not so easily categorized.***

I wouldn't say it's as simple as having a disability, but just giving us a little room to be something else first, before it automatically becomes that thing of "you are these inspirational disability dancers."

ROF – It sounds like a visual re-framing of your movement.

Y – People still cried. [laughter]

ROF – Can you please comment on that? [more laughter]

Y – On people crying?

E – It was a beautiful performance, it was aesthetically and emotionally beautiful and we did that.

Y – So, they didn't cry because we were disabled? One of these days, when I'm brave enough, I want to do a piece where I go on stage and eat a banana and pick my nose, as an experiment. Because I think that someone will say it's inspirational.

E - Yah, this idea that because we have disabilities we can do anything and somebody is going to say it's inspirational. As artists, as critical artists, there is something that is so annoying about that.

ROF – Personally, I feel like I know what it feels like to have that experience, "Oh, I breathed, and you thought it was inspirational. Wow, thanks!" Sometimes though,

you can tell that whatever the message or the image was - who knows what people get out of the art that you make? – but, you can tell that the audience was touched in a way that actually did reflect your artistry. And that is meaningful. And sometimes you can have both experiences in the same interaction with someone, and it's complicated.

Y – I like the piece that we did. It was a beautiful piece and there was a lot of emotion that we put into it, and I think that translated… I hope.

THE FUTURE

ROF - Any last thoughts either of you have about things you are excited to work on in the future?

Y – I'll just speak for myself. I don't feel like I have an ultimate goal. There's little goals and things I want to accomplish, like getting our website up! Creating more work, choreographing more, performing. So these are sort of ongoing things that I want to do more of. So, my focus is to do all those things.

> ***One of these days, when I'm brave enough, I want to do a piece where I go on stage and eat a banana and pick my nose, as an experiment. Because I think that someone will say it's inspirational***

E – I think that I've had two goals ever since I was a child. And one was to become a medical doctor, and that might always be a dream deferred, and the other one was always to be a successful artist, meaning that I make work with regularity, not just on the weekends. And that I mature, and that I show it. And that I am making art and am being nourished by it in a community of other people. What the actual goal looks like in the end, in terms of what kind of projects I do, I have no idea because I never imagined myself being a dancer. And now, I say I'm a multi-disciplinary artist, I'm a performance artist and a visual artist. Having the studio is the next step in saying that I'm realizing the dream now and I have a place to make work every day if I want.

Yulia Arakelyan From 2004-2005 Yulia trained with CandoCo Dance Company in London. In 2007, Yulia was the first wheelchair user to graduate from the University of Washington with a BA in Dance. Yulia has performed with Performance Works NW, Lilian Baylis Studio Theatre (UK), Long Distance Project, Impetus Arts, VSA Vision Gallery, University of Washington, The Headwaters and Scratch PDX. She has been teaching dance to people of all ages and abilities since 2006. Along with partner Erik Ferguson, Yulia founded Wobbly Dance in 2006. Wobbly has performed at Water in the Desert Butoh Festival, Boris and Natasha Cabaret, Art's Launch in Seattle and Polaris Dance Center.

Erik Ferguson is an anti-virtuoso movement artist living in Portland Oregon. He got his start studying improvisation with Alito Alessi in Trier Germany in 2003 and has performed and taught DanceAbility and contact improvisation throughout the Pacific Northwest, as well as the UK, Oaxaca, and British Columbia. He has most recently studied improvisation with Deborah Hay and Barbara Dilly, and Butoh with various teachers including Akira Kasai, Koichi and Hiroko Tamano, and Mizu Desierto. His performances range from storytelling to dance theatre exploring themes of embodiment, gender identity, and extremes of human emotion.



COLLECTIVE ACCESS, MUTUAL AID AND THE STATE

CARING FOR THE NEEDS OF SICK, DISABLED AND ELDERLY PEOPLE IN OUR COMMUNITIES - THEORY AND PRACTICE

Written in collaboration with Peta Pottinger

As a disabled anarchist and a strong believer in the idea of community and taking care of sick, disabled, and elderly people, I have spent many years asking the question: "How do we meet the needs of the people who are on the margins?" This essay will explore alternatives to state care models being created and tested by disability justice and anarchist communities with a critique of the oppressive nature of government and capitalism. It is an exploration of the achievements and failings of community efforts. Who ultimately cares for the needs of people with disabilities, the community or the state? What does an exchange of labor and resources look like when it does not involve money? How can spaces and support systems be provided that empower people of all abilities? For many disabled people and elders, accessible and affordable food, housing, transportation, and personal attendant care are hard to come by. Although many disabled people receive state benefits in order to get basic needs met, there are vast shortcomings in government systems.

I have spent years wrestling with the themes in this essay. Much of the content here is based on individual conversations I've had with a wide variety of friends and community members, most of whom are either elders or disabled, and have been involved in activist communities for a long time. In particular, this essay was written in collaboration with a close friend of mine, Peta Pottinger. The ideas contained here are based on our lived experience. Peta and I have both gone through catastrophic injuries and have experienced ups and downs in terms of support from the community and from the state. We are both anti-authoritarian activists with decades of experience in community-based collectives. Peta immigrated to the US from Jamaica at age 17 and identifies as non-gender normative. As a dark-skinned Black immigrant, Peta has had a different experience of disability than I have had as a white person born in the Pacific Northwest. We collaborated on this essay in an effort to start a conversation with the different communities we are a part of, to deepen the understanding of, and expand the vision of what community support could look like.

Author Aurora Levins Morales talks about the ecology of a community, how having people old and young, disabled and not, people of all types in general is vital to the health of the overall community, like how not just trees and soil, but also mosses and insects, are vital to the ecology of a forest. Like an ecosystem, we are also diverse. Access and support are complicated not only by age and ability, but also by other factors such as race, class, gender, and immigration status. Even though most people value the idea of a mutually supportive community, the individualist lifestyle and capitalist nature of our society is still prevalent, even in activist communities. Additionally, many of the projects aimed at providing mutual support and access still fail to meet the needs of society's most marginalized members, namely people of color, immigrants, transgender people, and disabled folks.

WHAT IS A VALUABLE CONTRIBUTION?

Disability justice activists promote the idea that a person can self-identify as disabled, and that claiming the identity of disability can be empowering and liberatory. Cultural models of disability often describe disability as an intersection of the culture the person is surrounded by, coupled with the environment and the person's abilities. Historically, however, the legal definition of disability was crafted by the US government and defines disability as when a person is unable to work a job because of an impairment. Although hundreds of alternative definitions of disability have been created since the government formed its definition, the state has systematized the way that our culture thinks of disability. The government likes to define people in two categories based on the ability to work and pay taxes: those who can work and those who can't. The foundation of our government is capitalism, and capitalism tells us we have no value if we do not make money. Similarly, the medical model of disability likes to define people based on constructed dichotomies of pathology: those who are sick and those who are well. What these oppressive systems have in common is that within the limited structures they have created, there is no way to understand or quantify the value of our contributions. Homemakers and seniors have shown us that work is relative. Just because you are not paid does not mean you are not making a contribution. There are innumerable ways to make meaningful contributions.

Russian anarchist and author Peter Kropotkin theorized that if a revolutionary end to capitalism actually happens, it will lead to an increased consumption of resources because people will no longer be living in hunger and scarcity. He claimed that in order to meet the needs of every member of society, every member would have to work hard and pitch in to feed and clothe everyone. In that sense, there is a push for every member to contribute what they can. And there is a push for every member to recognize the unique contributions of every other member. Learning to recognize the unique contributions of every member of society is a crucial step towards unlearning the capitalist notion that only a select few have valuable contributions to make.

THE CHALLENGES OF INDEPENDENCE AND AUTONOMY

The notion of independence is very limiting and very colonialist. It was the disability community that taught me to break down the idea of independence. Growing up, I learned from my working-class dad to work hard and never call in sick, even with walking pneumonia. I learned to avoid asking for help at all costs. He passed on to me what he was taught: classic capitalist values of pulling yourself up by your bootstraps. These are concepts that many of us who acquire disability or chronic illness must unlearn or complicate when we first become sick or injured. It can be a steep learning curve. For example, in my wheelchair, I can't reach groceries on high shelves at the market; I have to ask someone else to do it.

Once I started working in healthcare, the medical industrial complex taught me to prize independence as the end goal for all interventions. I was taught to quantify a person's independence using rating systems. For instance, to assess a person's ability to walk without falling, the Functional Independence Measure (FIM) can be used to quantify this on a scale from 1 to 7, indicating the level of independence from least to most. Rating systems like the FIM are promoted in healthcare because insurance companies reimburse clinics that get clients more independent. Numbers measure independence, a concept insurance companies value because it is a core element of capitalism. Yet, these are not systems that clients and their families understand.

Despite having long known the anarchist theories of mutual aid, it was the disability community that showed me, in practice, what interdependence looks like. Interdependence describes relationships where people are

mutually reliant on each other. My process of learning interdependence and unlearning independence has been a gradual one. As much as I love collective process, I tend to be a very independent person. When I became a feminist, as a teenager, my approach was very much, "I can take care of myself and I don't need anyone's help." Since becoming an amputee, I can't do a lot of things without assistance. I am learning how to be a feminist *and* be comfortable with accepting support.

Independence, the freedom from external control or influence, is similar to the anarchist value of autonomy, the right to self-govern. It is important to differentiate that autonomy and independence do not need to be synonymous. It is possible to be autonomous and interdependent in ways that are liberating for all people.

TAKING BACK STATE SYSTEMS OF CARE

It is hard to admit that in the world's wealthiest nation, there are millions without shelter, healthcare, or adequate nutrition. Despite good intentions from family, friends and communities, elders and disabled members of our society are not getting their basic needs met, particularly those from marginalized communities. I have no interest in being an apologist for the state, but it is true that the state sometimes gives people what the community doesn't. Millions in the United States are getting their rent, bills, and caregiver needs, at least partially met, by state-run programs. That's why disabled people and poor people suffer greatly when state services are slashed. Those programs provide people with housing, food, and weekly caregiver hours.

When state services are cut, the need for community support becomes more evident. An opportunity is created for us to learn what it could look like for us to give and receive support from each other in more meaningful ways. The Great Recession created economic hardship across most communities, and it made the need for community support clear to people who hadn't needed support before. By allowing the state to control systems of care for people who need it, we are consenting to the oppressive treatment the state gives to people who receive state services.

In David Beito's book, Mutual Aid to the Welfare State: Fraternal Societies and Social Services, 1890-1967, he describes how member-driven projects were created by communities to fill specific needs in communal ways. For example, the African American fraternal group The Knights and Daughters of Tabor in Mississippi opened Taborian Hospital in 1942 to serve the medical needs of the Black community at a time when many Black people were denied services from other hospitals. Beito also describes how the state took over grassroots organizations and made them charitable projects rather than reciprocal giving projects. Charitable projects claim to give resources with no expectation of getting something back. Yet, that is often not true. Charitable organizations often want something in exchange for their gift such as photo opportunities or tax breaks. There is stigma attached to receiving charitable donations, and the manner in which these donations are given can often feel tokenizing to the person on the receiving end.

WHAT THE STATE IS GOOD AT

I was on benefits for ten years. During that time, the state gave me medical coupons, food stamps, and money deposited into my account every month. I had almost no choice about going on benefits. I needed the health care, and I needed a roof over my head. End of story.

There are a number of things the state does well. It recognizes that essential needs like food, housing, transportation, healthcare, and monthly income are crucial for survival and must be provided. This is achieved through systems that provide food stamps, subsidized housing, busing and transport services, medical coupons, and monthly checks. These resources all arrive on a scheduled timetable.

The state is consistent; it consistently oppresses people by being generally demeaning and frustrating to work with, and it also consistently sends a check, food stamps, and a medical coupon on the same day every month. It provides far less than what a human being actually needs, but it does provide regularly. State systems are profoundly flawed, but they are set up to serve millions of people.

In terms of personal attendant care, the state recognizes the daily need for bathing, toileting, and feeding. State-appointed care attendants are poorly trained and underpaid; however, they offer a necessary option for people without family, friends, or a significant other who can provide consistent care. A friend of mine with quadriplegia is grateful for her state-appointed caregivers. As she aptly put it, "I don't necessarily want my close friends wiping my ass."

On the topic of relying on the state for care, Peta says: "We should be able to use the systems that are there. It doesn't mean you sold yourself out. Sometimes you have to look outside of your community to learn something important. We should be able to adapt and improve the systems in our own communities."

STATE BENEFITS AND THE MATH OF DIVIDING YOURSELF

Community alternatives to state programs are vital. There are a lot of things that the state does wrong, such as pathologizing people's lives, identifying people as disabled just because they can't work a job, denying people as disabled because they don't meet state-sanctioned criteria, and stealing our privacy. The list goes on and on. Having one's life entrenched with the state means they have access to every bank account, every bank statement, your social security number, the social security number of everyone you live with, whether you share food with people, and changes in your income of twenty dollars or more. Being an anarchist, it was very hard to give up my anonymity and personal information so freely to the government. Yet, there was no way around it unless people in my community paid my rent, my bills, and provided all the care I needed.

In Peta's experience, "A state-employed social worker came to my house and evaluated my room and based my needs on that. I don't like the state coming into my room, but I've had that happen several times. Also, I've had to learn how to negotiate bureaucracy. The states make things so difficult sometimes. It's really hard. I'm still confounded by the process. But there's no choice. You have to do it, and you have to figure out how to do it, otherwise who will pay your rent? You have to be nice to people, even if they're being really horrible to you. With state-funded transportation, the driver will say and do inappropriate things all the time. You could spend all your time complaining. But getting a ride to an appointment and a ride home is primary."

The shortcomings of state programs are vast. Many applicants are excluded because their health situation does not meet the narrow criteria of the state. Many are unable to successfully navigate all the bureaucracy of the state, filling out the forms, returning the phone calls, and attending the appointments required. The communication requirements alone create barriers that are compounded by language, cultural differences, as well as cognitive ones. When I applied for Social Security Disability, I was privileged enough to be accepted on the first try because I have bilateral amputations, and my disability is easy to document. In contrast, a friend of mine with Multiple Sclerosis had to go through rigorous testing that involved rating how "unfit to work" she

was using a percentage system. She said, "They told me my arms are 75% disabled, but my legs are only 50% disabled". I have a number of friends whose disabilities are complicated to document, who had to apply multiple times before finally being approved, and I have at least one friend who, despite great effort, was never approved.

The government puts us in situations that cause us to question our integrity. Depending on the situation, there is a push to present your abilities one way or the other. At the food stamp office, you are put in a position of emphasizing every possible problem you have in order to prove your disability. For example, I rolled into most of my food stamp appointments in my wheelchair, even though I could have walked, figuring it couldn't hurt. This is the medicalization and pathologization of the disability experience – learning how to perform your disability so that others can see it. The performance of disability is strategic because it can gain sympathy and get us what we need. Seminal anarchist author and publisher Colin Ward said, "The positive feature of welfare legislation is that, contrary to the capitalist ethic, it is a testament to human solidarity. The negative feature is precisely that it is an arm of the state."

A few years after Peta's health crisis, I asked her, "How has your perspective on the community and the state changed in your process?" Peta's response was, "My ideals about the community have changed. I grew up in a Caribbean community. I grew up in a community where we did more for people; elders lived at home, you didn't send them away. I'm not saying it was perfect. Class had something to do with it; poor people are used to sharing the little they have. Some of the people provided for by the state are the people that society doesn't want to see at all. I rely on the state a lot more than I ever thought possible, and I hate it because I've always wanted the opposite – to be as separate from the state as possible."

MUTUAL AID

Having worked fourteen years in an anti-authoritarian bookstore, I have been exposed to a lot of people's ideas about what "community" should look like. When we talked about the goal of our bookstore it was not just to sell books. Our goal was to create a community space where people could educate themselves and connect with others with the ultimate goal of building a liberated community that would smash the state and end capitalism.

Core values of anarchism are the critique of government, nation states, borders and capitalism, and the promotion of self-governance and non-hierarchical structure within group organizing. Beyond these values, there is a significant amount of disagreement among anarchists regarding the goals we're striving towards. In his 1995 essay "Social Anarchism or Lifestyle Anarchism: An Unbridgeable Chasm", anarchist author Murray Bookchin lays out the inherent divide within anarchism, those who prioritize individualism, and those who are motivated by a community-based vision of anarchism. This inherent divide has made it difficult for the anarchist movement to find unity among its ranks and to achieve relevance to a wider group of people.

Lifestyle anarchism prizes personal freedom and autonomy; its essence is independence. Social anarchism centers a desire to build societies together that promote collective freedom, while also caring and providing for each other. If combined, these theories support both the notion that elders and people with disabilities can be autonomous individuals as well as participants in communities building collective liberation.

In 1902, Kropotkin coined the term "mutual aid", the idea that by sharing together resources and skills, reciprocally and voluntarily, there can be mutual benefit. Examples of mutual aid are widespread, such as libraries, free boxes, credit unions, and carpools. Mutual aid-inspired projects are typically free and voluntary

for participants. Mutual aid projects are typically non-hierarchical structures with no boss or president; they are member-led and member-organized, and are often non-profit organizations. Mutual aid differentiates itself from charity-based programs because all members not only receive services but also give them, as well.

Kropotkin's classic book *Mutual Aid* promotes the idea that people can cooperate together to accomplish things. *Mutual Aid* offers an alternative to the theory of social Darwinism, which promoted eugenics and the development of a master race. Kropotkin observed that if people eschew competition and focus instead on collaboration, the culture will inherently center mutual benefit. In another book of his, *The Conquest of Bread,* Kropotkin wrote about how scarcity was unnecessary and he proposed a system of economics based on mutual exchange. Although Kropotkin has been accused of being an optimist, and later in life he even criticized himself as having some unrealistic ideas, he does envision a communal way of living that could be empowering for all members. He believed we should not fight for the right to work, but for the right to live, and for the general well-being of all people. He believed that working for a boss should not be the goal, and concluded that non-hierarchical cooperation and mutual aid are not only essential, but they are the most important factors in the evolution of species and the ability to survive.

The core concept of mutual aid is reciprocal giving. One challenge with this system occurs when the contributions made by individuals are not valued equally. Some mutual aid projects are built on the premise that the more work you put into something, the more you should get back. In other words, if you are only able to contribute a little, or if others consider your contribution small, then you will only get back a small amount. Although it may not be the intention, this is an inherently ableist structure because not all members of a group are able to make equal contributions. Marginalized people experience more barriers to resources, even in intentional communities, unless consideration is given to creating equitable systems of access.

WHEN THEORY LACKS PRACTICE

I am committed to the ideals of anarchism, because the vision of anarchism, specifically around more equitable divisions of labor and resources, and building communities without hierarchy, gives me hope. Yet, despite the vision, the reality is that ageist and ableist divides are rampant and often unchecked in most anti-authoritarian communities. These divides make it relatively impossible for elders and people with chronic illness and disabilities to access mutual aid services. I see very few elders, poor people, homeless folks, and disabled people utilizing free boxes, free schools, and co-ops. The people who set up these projects often come from privileged backgrounds and devise projects that only serve their homogenous social groups. Or, despite being well-intentioned, they have not thought about how to make their project available to the marginalized people in our communities who could benefit most.

In general, I am concerned with how theory is put into practice, because it is clear that despite ideals about taking control back from the state and building a liberated world, there are still people in our neighborhoods whose basic human needs are not being met every day. I see little concrete support given to the members of our community who are on the margins. Although there are elders and people with disabilities in anarchist communities, they are few and far between and often participate despite the lack of support and acknowledgement they receive, not because of it.

COLLECTIVE ACCESS

Collective access is an idea that comes out of the disability justice community. This idea developed from the recognition of the unique gifts of disabled people. It emphasizes what we can do and gives us a vision for offering our abilities to each other in mutual exchange in order to increase access for all participating members. For example, grocery shopping and housecleaning are physical challenges for me on days when I can't walk. A friend of mine, who has cognitive impairments, struggles with bookkeeping and answering emails. If my friend cleans my house and I answer his emails, we create collective access, accomplishing tasks together by pooling our resources. The idea behind collective access is that we do not have to be independent; that perhaps our quality of life and goals can be better met by working together.

Collective access teaches us to offer only what we have the capacity for and no more. This is no small thing. Accepting assistance brings up a lot of guilt and awkward feelings for most people. American ideals seem to crumble if we admit we need help with something. Collective access, when put in practice, can be extremely healing for resolving these awkward feelings. In an ableist society that tells us we have little worth, little capability to accomplish things, collective access tells us something different. It highlights what we can offer and allows us to share that with others in ways that are mutually beneficial. Collective access gets things done. It builds self-esteem. It connects us to others. It gives us a sense of unity because we are working together. It helps us not feel alone. It helps us not feel "needy," because we aren't just receiving; we're giving as well.

Sick and disabled activists are regularly accused of not doing "real" activism by people who think it only counts if you show up at meetings or protect in the streets, and the activism that happens online or behind the scenes doesn't count. This is a very limiting, ableist notion of what activism can look like. In fact, collective access is a very powerful form of activism that all communities can learn from. Every community has sick, disabled, and senior members. People of all ages and abilities benefit from collective access. Every movement, every neighborhood can learn from this practice.

For those who engage in creating collective access, whether in informal ways between friends and family, or in structured ways, like in committed collective access networks, the results can be empowering and healing. These relationships can build intimacy between those who participate. Intimacy can reduce isolation, one of the primary hardships experienced by marginalized people.

Some people critique collective access for not being as easily accessible to people with higher-level access needs. For example, some friends of mine who are quadriplegic, who cannot get in or out of bed without physical assistance from another person, who need assistance throughout each day for toileting, bathing, and other intimate forms of daily care, feel that collective access only goes so far. Another critique is that many community members are not ready to provide intimate care, like a bowel program. Not everyone has the patience or understanding to spend three hours doing a morning program getting someone out of bed, ready and groomed for their day. Some argue that when community members do agree to provide this level of assistance, it is often with unspoken emotional expectations of emotional labor, such as "I bathed you, now you get to listen to me talk for two hours about my alcoholic boyfriend." A concern is that the emotional needs are often not equated as being part of the exchange. They are not recognized. Another challenge is that many people who provide assistance for intimate levels of personal care do not understand that the interaction is not necessarily a social one. The point of the interaction is to provide care and access. The person receiving assistance may not feel up for a social interaction, but they do need help getting their basic care needs met.

Putting collective access into practice requires self-knowledge, initiative, communication, commitment, and consistency. Unfortunately, many of the people who could benefit from collective access also have some internal barriers to participating. The path to self-acceptance of disability and illness is a tough road, and not necessarily a linear one. Many of us are in different stages in our process of healing all the things we've been

through and are going through. Even people who claim pride in disability can have shame in admitting the need for assistance with tasks. Capitalism and ableism tell us that we should be able to pull ourselves up by our bootstraps. Internalized ableism tells us we aren't worth it and don't deserve the help. Collective access has the power to heal these internal wounds.

COMMUNITY CAN BE GOOD IN A CRISIS, BUT WHAT ABOUT THE LONG HAUL?

What happens when the excitement of donating to someone's health crisis crowd-funding site is over, and months or years later that friend is still sick? Communities often don't know how to address issues of capacity in order to sustain their inclusion of people with disabilities in the long term.

Peta says, "I see non-disabled people talk about stuff, but not take in what disabled people in the community are going through in an everyday kind of way. Liking a blog post or attending a fundraiser are simple steps toward being an ally. The harder step is to make a deeper change in culture, community-wide. We have to get beyond where we are." Community is often better about meeting short-term needs at the beginning of an illness, when it's a crisis point. "A friend of ours is in need!" People put out a call for help, start a crowd-funding site, create a short-term care schedule. However, if the person's illness or disability becomes chronic or permanent, attention wanes. People stop thinking about it, or start to experience compassion fatigue, a gradual lessening of compassion over time - a condition common with caregivers and healthcare providers. This phenomenon is understandable, but it's crucial to move beyond crisis-driven approaches to care and care for each other sustainably.

GROUP HOUSING AS AN ALTERNATIVE TO INSTITUTIONAL LIVING AND HOMELESSNESS

Poor people have the hardest time finding accessible, affordable housing. Among poor people, it is immigrants, elders, and the disabled who experience the most acute challenges in obtaining housing. Many elders and people with disabilities are living on fixed incomes, and most are living under the poverty level. It is an unfortunate situation that most affordable housing situations are not accessible in terms of architecture or location, so many people are forced to choose inexpensive housing that does not actually meet their basic needs. An even more unfortunate situation is that a disproportionate amount of people with disabilities are unhoused because accessible housing is not available.

Rent and utilities are the biggest monthly expense for most people. After Peta's health care crisis and mine, the need for affordable, stable housing became a necessity for each of us. Group housing is an attractive alternative to institutionalized living or having no place at all. It costs less money to live with other people, and it's more social than living alone. In Seattle, there are a number of group houses, collective houses, and land trusts. Yet, after losing my legs, I had to move out of my group house because it wasn't accessible, and both Peta and I have been denied a room in a group house. Disabled people and elders experience unique barriers to housing. Architectural barriers, such as stairs without a handrail, are only one type of barrier. A general lack of understanding about the disability experience is just as powerful a barrier. Many group houses do not

realize they discriminate. It is when the details are negotiated that the discrimination becomes most clear, particularly to the applicant. The number one issue that comes up is the cost of rent. A disability check is small; in 2004 my check was $600 per month, and that check had to cover rent, utilities, and everything else except food. Most people on Social Security cannot pay much. Sometimes group houses will let a roommate pay less rent in exchange for doing more chores around the house, but if the roommate is limited in what chores are possible, the price of rent goes back up. Also, many group houses are willing to accommodate things like wheelchair access, but not, for instance, a service animal. Accessible bathrooms are even harder to come by. Peta had a housemate who moved out of their land trust-operated collective house when she retired because the culture of the house was not conducive to her needs.

NEGOTIATING GROUP HOUSING

In order to address conflicts in group housing arrangements, communication skills are required. Assumptions can be made on both sides. A group house can assume the needs of a disabled applicant, and applicants can make assumptions about what a group house can offer to them. Assuming that the house must provide for all the needs of every member of the house is unrealistic and daunting, especially if members of the house have diverse needs. Longstanding housing projects typically have systems set in place for how they operate. There can be fear or resentment about wanting to change the system in a group house to accommodate someone new. Even very generous people can become uncomfortable, even fearful, when dynamics in their home are changed.

Non-disabled people sometimes feel they are being pushed beyond their capacity when a person with a disability or chronic health issue moves into their house. Where does this feeling of overwhelm come from? At the root, it is likely a combination of ignorance, ableism, poor communication, and a misplaced sense of guilt: "I should be doing more". Unpacking these emotional reactions is the first step in being aware of and combatting ableism.

Fear can be a two-way street. There is a lot of fear involved for housing applicants around choosing what to disclose and what not to disclose. There is a desire to be honest, and there is a fear that honesty may carry repercussions. People with disabilities are often given ableist messages that our needs are too much, and because of this, a cultural fear has developed that we will be perceived as needy. It is because of this fear that we minimize our needs and do not fully communicate them upfront. Problems can develop quickly if our basic household needs are not properly communicated. Even though in the US, we are legally protected to not have to disclose our disabilities or age if we do not want to, there are times when it is advantageous for us to disclose. The process of communicating through these barriers is extremely complicated and personal.

Intersections of gender and race further complicate negotiations around chores, rent, and household needs. Peta has an example around negotiating chores in their housing situation. Chores like answering emails and paying bills are not accessible for Peta. Yet, Peta is excellent at gardening, yard work, pet care, and cleaning and is generally happy to do those tasks to contribute to the household. However, depending on who Peta is living with and the house culture, the way value is placed on these contributions can vary. An uncomfortable dynamic sometimes develops where Peta is made to feel like their contributions are not valued because of the way that race and gender interact with where value is placed. This dynamic has made Peta feel relegated as the black maid in the house rather than a housemate. With these dynamics already weighing heavily, it is an added burden to a person with multiple marginalized identities to advocate for oneself and say things like, "I can't pay

that much rent. Do you have a cheaper room or a sliding scale rent policy?"

Disability justice gives us the permission to share what we can and can't do and, through collective access, find solutions where all can thrive. Author and disability justice visionary Mia Mingus offers the tool of stretching for each other. Mingus says that in order to connect and build relationships with each other, there will be challenges. In order to bridge the gaps, we need to stretch for each other and compromise.

DWELLER CONTROL AND SPACES FOR ALL

Dweller control is the idea that the people who live in a space should be involved in the design, management, and maintenance of the space. Employing the principles of dweller control is an important step toward creating liberatory living situations for all people, particularly marginalized people whose needs are not met by the average living space. "From an anarchist point of view, dweller control is the first principle of housing", said Ward, who during his life studied architecture and city design, and wrote and spoke prolifically about the connection between anarchism, design, and creation of space. Anarchist thinkers have envisioned not only how spaces should be designed but how communities should be built. Ward believed that squatting, the occupation of unoccupied buildings by unhoused people, and intentional communities are not mutually exclusive: "I think squatters' campaigns, as well as providing a roof for homeless people, are significant as symbolic changes to the concept of property and for their effect on the participants". The spirit of Ward's ideas encourages societies to build intentional communities that are tenant-led and operated. The idea of dweller control dovetails nicely with the concept of universal design, which promotes that spaces and products be made accessible for all people and that the communities who will utilize the space or product should be involved in its design.

SYSTEMS OF COLLECTIVE CARE RAINBOW ASSISTANCE PROJECT

In the 2000s, in Seattle, we attempted to launch a project called Rainbow Assistance Project (RAP). Our goal was to establish a community-run chore worker program for seniors and individuals with disabilities from the LGBTQI+ community. The program was designed to support folks who were low-income and needed assistance with chores, such as lawn mowing, shopping, laundry, and furniture moving. To ensure that volunteers were culturally competent and equipped to serve the LGBTQI+ community, we partnered with an existing chore-assistance program. Though this program already offered chore assistance services, volunteers lacked specific training in serving the LGBTQI+ community. To address this gap, RAP collaborated with the program to provide LGBTQI-specific cultural competency training to volunteers. Our intention was to pair RAP-trained volunteers with clients. However, our efforts were thwarted when the non-profit we were affiliated with, Verbena Health, was abruptly shut down due to embezzlement by its executive director, Michelle "Mo" Malkin. Malkin was subsequently indicted on federal charges. As RAP was just beginning to take off, it was abruptly terminated. Despite the community not resuming the project, the concept of a community-run chore worker program remains a good one. These programs not only help local community members meet their daily needs but also foster intergenerational relationships, friendships, and a deeper understanding of the lives of people in our communities.

SHARE THE CARE

Websites like "Share the Care"(STC) have become really popular. STC encourages caregivers to avoid burnout by sharing the care for a loved one with chronic illness. STC promotes the idea that if a group of people shares caregiving responsibilities, rather than letting all the responsibility rest on just one person's shoulders, that caregiving can be more sustainable and potentially long-lasting for everyone involved. If friends and housemates simply state what they can't do, and offer no more than what they have the capacity for, caregiving can become more sustainable. There is also an opportunity here for the people receiving care to state what types of support they need, and potentially what resources they also have to offer.

CARE COLLECTIVES

A friend of mine has a care collective of friends who do weekly shifts in order to meet his caregiving needs. He's been able to develop long-lasting and intimate relationships with these friends through the care collective. Another friend of mine owns a house (from a settlement she got from the car accident that caused her spinal cord injury). She's a single mom and lets friends live in her house for free in exchange for assisting with caregiving, parenting duties, chores, and errands. Another friend of mine, who has several chronic medical conditions, has an ongoing schedule of friends who do care shifts regularly for tasks like shopping and cleaning. In small groups, interdependent collective access groups are being formed between elders and people with chronic health needs. These relationships can be enriching, empowering, and necessary for meeting basic access needs. They also build intimacy and self-esteem by emphasizing each other's unique gifts.

SHARING FOOD, INCOME AND RIDES

Community-run projects are making a significant impact in addressing food, economic, and transportation justice. Food banks, co-ops, bulk food-buying groups, community gardens, food forests, soup kitchens, food not bombs, and community meals are all examples of inexpensive and accessible ways to provide food to those in need.

Sliding pay scales are a great example of economic justice, where individuals pay what they can afford. These systems work well when those who can pay at the top of the pay scale do so. Living in poverty often means that when things like clothes, cars, and technology break down, it can be difficult to repair them. Friends and community can offer to help fix things. Micro-lending systems provide loans to groups of people who hold each other accountable for repayment, making receiving loans possible for individuals who might otherwise struggle to obtain an individual loan. Microlending has been particularly beneficial for women and people of color. Credit unions offer an attractive alternative to national banks that charge high fees and lack investment in the unique needs of local communities.

Group phone plans are a way for groups of people to save money by clustering an expense.

Transportation access can take many forms. Organizing for affordable bus routes and rail lines that serve all neighborhoods is crucial for making transportation accessible to everyone, especially those with mobility limitations. Ride-sharing, car-sharing, and carpools are other methods to reduce the burden of transportation.

BEING THOUGHTFUL BUILDS INTIMACY

Even if you can't sign up for a regular shift, simple acts of solidarity go a long way. Individual people's needs are specific, so it is usually best to ask the person directly what kind of support they are looking for. If they want to exchange support, they can tell you, and if they just need to receive support, they can tell you that, too.

Making your home an accessible space is a huge move towards solidarity. For example, build a wheelchair ramp, or make your home a scent-free space so that friends who can't do stairs or be around scented products can still visit you at your home.

Approach people you know about trading for services. Perhaps your friend or neighbor possesses a skill you're unaware of, or you might have a skill you didn't realize was worth exchanging. Many people require support, such as pet care, like rides to the vet, long walks for dogs to get exercise, feeding, grooming, and training. Cognitive support can be beneficial. For instance, a close friend struggling with impulse control spent excessively on shopping. A roommate helped him return the items he was buying, preventing him from overspending within his budget. Emotional support can be incredibly fulfilling and natural to offer. Ways to do this include spending quality time with people, getting to know them better, checking in on friends and neighbors, and simply asking, "How are you doing?" Simple gestures like phone calls, texts, and emails can make a significant difference. Additionally, many individuals with health conditions face othering, where false dichotomies are created, such as, "I'm not vulnerable, they are." Sharing experiences and exchanging vulnerability helps break down these constructed barriers, one relationship at a time. In general, consistent and thoughtful friendships are invaluable.

Caregiver hours are often in short supply for most disabled people. For instance, when Peta was recovering from an injury, a generous community member paid for a personal assistant to help Peta fill out forms, make medical appointments, and respond to emails. A friend with daily personal care attendants generously donated one of her caregivers to someone else who had been hit by a car, ensuring that person received immediate care.

TAKE PART IN CARING COMMUNITIES

Access to affordable housing, transportation, healthcare, and food are fundamental human rights that all people can get behind. However, finding a simple solution to addressing these issues for ourselves and our communities is challenging. Elders and community members with chronic illness and disability have been contemplating these issues for years, but due to the lack of accessibility in many spaces, including activist spaces, these conversations are not being brought to the center. To truly build liberated communities, we must connect with the communities we are already a part of and those we are yet to join. By recognizing our shared connections, we can foster a sense of unity and collaboration.

Peta Pottinger is a writer, gardener, and cultural worker who recently relocated to Seattle, Washington. Peta has decades of experience with anarchist and coop projects including membership in Bay Area Anarchist/Anti-Authoritarian People of Color, the Network of Bay Area Worker Cooperatives, Modern Times - a collective bookstore in San Francisco, and the Western Worker Coop Conference, and has spent decades living in intentional housing communities with radical frameworks. When not doing collective work, Peta likes to be found with hir hands in the dirt, dreaming of food justice and scheming about collaborative writing projects with other artists and activists.

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RIDE
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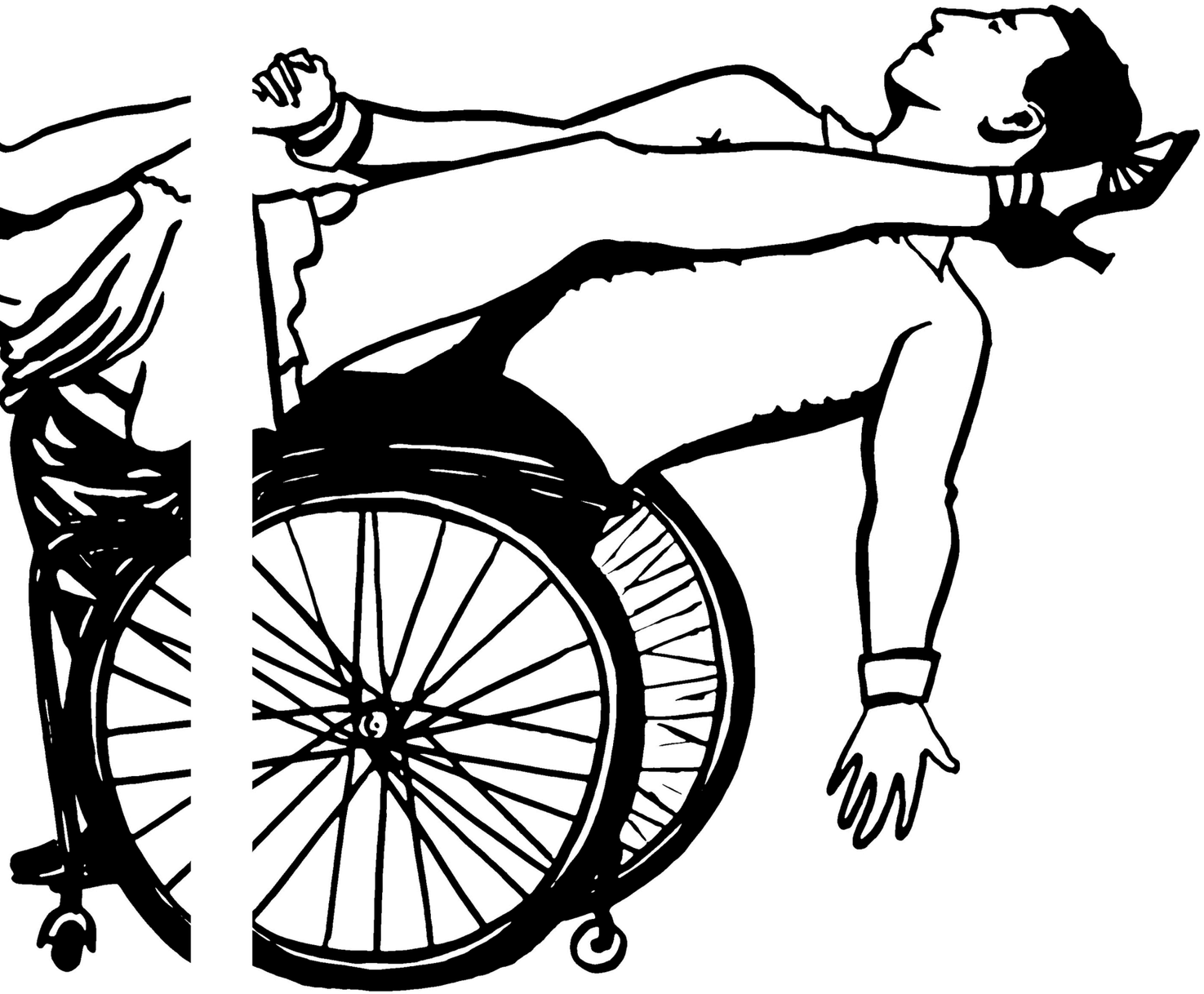

DOWN BY ME

Crawl in the dirt with me
Get down on the floor
You pave the way some
I'll pave some more

Sit down by me
Roll down with me
The shoreline is close
And the road not too rough
We can make it by sunset
If we tighten up

Lie down right here
Close by near me
There's pillows
By the windows
Watch the night sky go by
From here

2012

ET RUSSIAN is an author, performer and filmmaker living in Seattle, Washington. Russian has published work in *The Collective Tarot* and *Gay Genius,* has performed in productions by Sins Invalid and Light Motion, co-founded the Seattle Disability Justice Collective, co-directed the movie *Third Antenna: A documentary about the radical nature of drag*, and was a recipient of the 2013 Harlan Hahn Award in Disability Studies from the University of Washington. Learn more at ETRUSSIAN.COM.

THE RING OF FIRE ANTHOLOGY

is a collection of the zine from the late 1990s, featuring new material never before published. *Ring of Fire* is honest, engaging, and ahead of its time.

Alternately emotional and erotic, funny and political, *Ring of Fire* captures the work and words of artists and leaders shaping disability culture and history, and also tells the author's story of healing from a traumatic accident at a young age. A young feminist steeped in the cultures of queer and punk, Russian embraced a cultural identity of disability while writing *Ring of Fire*. Years later, after discovering the disability justice movement and getting a job in a hospital, Russian examines what it means to be on the giving and receiving end of healthcare in the United States, and the challenges of working with a disability.

Through black and white ink drawings, comics, linoleum block print portraits, essays and interviews this collection explores connections between science, culture, bodies, disability justice, sex, class, race, healing and the politics of work.

ET Russian's work has taken my breath away on more than one occasion. At once deeply thoughtful and bold, political and human, Russian's work stirs our collective magnificence in service of our liberation. Russian has continuously contributed so much to disability justice work and community and I have no doubt that *The Ring of Fire Anthology* will do the same.

– Mia Mingus, author of *Leaving Evidence*

The Ring of Fire Anthology is beautiful, sexy, and thought provoking all at the same time. If ever you've needed stories, art, poetry, and bad-ass rabble-rousing that connect disability and queerness, sexiness and radical anti-capitalist politics, look no further. ET Russian's vivid work lives and breathes these connections.

– Eli Clare, author of *Exile and Pride*

Ring of Fire is one of the zines that had the most significant impact on my thinking--it totally blew my mind when I encountered it in 2000. I am thrilled to see gripping material from ROF combined with insightful, transformative new writing and images about disability justice, health care, art and activism being distributed as a book. A whole new generation of activists will now get to use these materials to reexamine their communities and transform the world. ET Russian's clarity, honesty and insight is a phenomenal contribution to today's activists building disability justice tools and frameworks in multiple movements and communities.

– Dean Spade, author of *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of Law*

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