DISTORIES

by DISTORIES | Issue 12.1 (Spring 2023), Crip Pandemic Life: A Tapestry

ABSTRACT DISTORIES is a small open-source and open-access Instagram zine project, gathering testimonies from disabled contributors. This project began in the context of the summer of 2021, as mask mandates and general precautions around COVID-19 were being relaxed. Each chapter of the zine is introduced by a question, framing stories and snapshots of experience as well as demands, affirmations, and dreams shared by contributors. The project was stewarded by geunsaeng ahn from September 2021 to July 2022.

KEYWORDS disability, crip, pandemic, COVID-19, zine, Instagram, visibility

Curatorial Note

For the present excerpt, sections editors Theodora Danylevich and Alyson Patsavas selected chapters 2, 3, 4, 9, 11, and 12—six out of the total of twelve chapters of DISTORIES at the time of this writing. Our aim in curating this excerpt was to share selections that we felt convey the breadth of what DISTORIES contains—from recording painful interpersonal losses and ruptures in trust and community to stories of interdependence and care; from cries of rage to scathing cultural criticism in the shape of specific demands; from expressions of affirmation and solidarity to calls and visions for radical new worlds. Some—many—of the excerpts express gradients of rage, resentment, desperation; and may elicit a breadth of feelings, in response. While we recognize that some readers may find some of these excerpts difficult or discomfiting, these voices are necessary to include, and paint the larger picture of disability experience during the pandemic. We kept intact the entire set of contributor voices for each chapter, and only lightly edited for typographical errors that might cloud meaning. The questions addressed by each of these chapters are:

- 2: “How has the pandemic impacted your relationships?”
- 3: “How do you feel about ‘most’ of society ‘reopening’ at this stage in the pandemic?”
- 4: “If you could tell society what we could be doing better for our community, what would you like to tell them?”
- 9: “What would you like to demand from your friends, family, community, and/or society right now?”
- 11: “Do you have an affirmation that you would like to share with our community?”
How Our Contributing Authors Identify*

Actively Grieving
Agender
Artist
Art maker of many trades
Autigender
Bigender
Bipolar
Black Woman
Blasian
Brown
Chinese
Chronically Ill
Chronic Pain Sufferer
Chronically Pained
Crazy
Crippled
Crippunk
Crazy

Queer
Sex Worker
Sick
Sober
Someone with a Chronic Medical Condition
Spoonie
Student
Taurus
Third Gen Dutch & Scott Canadian
Trans
Transgender
Trans Genderfaun Bringer of Joy
Young
Zero Generation

Disabled
Disabled Immigrant
Displaced
Dyke
East Asian
Ex-Skid
Genderfucked
Immigrant
Immigrant from Bengal
Immunocompromised
Korean
Mad
Mentally Ill
Mixed Heritage
Muslim
Neurodivergent
Non-Binary
Poly
*Identities listed are from the sixteen authors’ own descriptions of their identities from submissions as of July 2022.


Figure 1. DISTORIES flyer.

Submissions are ongoing at tinyurl.com/DISTORIES <https://www.tinyurl.com/DISTORIES>.
Zine (selections)

Cover

DISTORIES

Ongoing testimonies from the COVID-19 pandemic by authors who are

DISABLED
SICK
CHRONICALLY ILL
IMMUNO-COMPROMISED

+++
THE INTENTION OF DISTORIES

Distories welcomes all disabled, sick, immuno-compromised, chronically ill, chronically pained +++, folx to share their fully uncensored experiences regarding the able-bodied "reopening" of the world during the covid-19 pandemic (summer of 2021) and other impacts that the pandemic has had on our lives.

The primary hope of this project is to help us feel less alone by seeing more of our experiences amongst the algorithms.

The second hope of this project is to confront able-bodied world in its perceptions of "access" and to be an ongoing reminder that our comm-unity is still here.
May this effort uplift and visibilize our experiences that continue to remain unwritten, unspoken, and unseen.

To honor the labor of the authors, please consider sending them monetary gratitudes through their payment platforms provided at the end of their stories.

The development and publishing of these stories will be at a slow pace (by ableist standards) due to members who are the caretakers of this project also being disabled, chronically ill, chronically pained, and immunocompromised. To this aim, please be mindful of this in the monitoring, development, and expectations of this project.
HOW HAS THE PANDEMIC IMPACTED YOUR RELATIONSHIPS?

“Finding support and meaningful connection in the pandemic has proven to be quite challenging. Allistic, and able bodied friends have mostly disappeared from my life into their own cliques, which I understand because the pandemic really reinforced people to huddle into affinity groups for survival. But where does that leave us melanated autistic and disabled folks functioning on criп time? My friend circle now is mostly disabled, sick and autistic long distance friends and I am amazed at the openness and the support they are always willing to give in spite of always being low capacity.”

Sarmistha Talukdar  
(they/them)  
@tavish.experiments  
Venmo: @Sarmistha-Talukdar

“its been a mixed bag, in many ways its increased the distance between some relations and in other ways made reaching out and meeting up (online easier).”

Meera Ghani  
(she/her)  
Twitter: @meeraghani

“The pandemic actually strengthened my relationship between my partner and I. I had to put faith in him to protect the family as he went to work every night and depended on him to get the food and other resources that we required through the months, including picking up my medicine.

We sat down more to talk and discuss our worries and what we wanted from each other and our family as a whole. We delegated jobs in the house according to needs and safety which helped to decrease stress. We started a motto, ‘Better Together’ as we worked more with each other rather than to fulfill our own needs.”

Kyoko Heshiimu  
(She/her)  
Instagram: @dragonmom8  
Cashapp: $KyokoHeshiimu  
Facebook: @ Eko Speaks Art
“The pandemic has made me feel more insecure and ashamed in my relationships. Especially when trying to assess which of my relationships can really hold space for humility, understanding, and the ‘checking’ of able-bodied fragility/discomfort that comes with being in relationship with me (and my illnesses).

I try to give everyone the benefit of the doubt as I watch folx (on social media) out and about disregarding cautious protocols that could help protect our disabled, sick, ill, and high-risk community — and likely help us end the pandemic (and the next one that is likely coming) sooner.

I try to have empathy by reframing that maybe these folx likely have other things going on in their lives where they are willing to be more risk inclined with their exposure at this point. Because they need to engage in ableist-leaning actions because there aren’t other outlets to escape from the grief and suffering that is constantly in everyone’s face all the time. I am basically constantly having ‘both/and’ existential crises everyday to reckon with these thoughts analyzing other’s actions.

It takes a toll on my heart because I have seen even less outlets for folx like us to use, go to, or places to even go ‘out’ to for ‘disabled world’. So I end up with a lot of unwanted feelings of judgement, shame, and jealousy. It makes me hate my self and the body I’ve been forced to be in.

When I see my community members maskless in places or in high volume crowds, parties, cross-contaminating their care pods, etc I feel a huge trap door opening beneath me in the connection I thought I had with them.

It makes me feel like the values I shared with these folx I deeply care about are being discarded, betrayed, and abandoned. It hurts my heart because it reminds me that community care within able-bodied parameters always has a finite limit.

I then start to spiral by isolating myself even more to self-protect (which isn’t helpful). At the same time, I’m terrified of being forgotten because I can’t ‘show up’ in the same way that everyone else can who are more physically present (and able-bodied) in each other’s lives right now. Either way I feel that I end up alone.”

gunsaeng ahn
(they)
@ahntologies
PayPal: gunsaengahn@gmail.com

“It has given me more space within myself. It has given me a more realistic view of what’s possible for me. Lots of alone time and time with my cat. It has also made me grateful for the friends I have, who are mostly queer and neurodivergent, because I feel that we appreciate each other more while going through this past two years.”

Tai
(they)
@FelineForestMedicine
Venmo: @TaiCK
PayPal: PayPal.me/CranioWithTai
Zelle: 845.915.0798
“I have lost 2 of my best friends. People I spoke with on a regular basis. We drifted so far, and it felt like they were petty arguments but I realized very quickly how self-centered they were and that they weren’t nearly as invested in building and maintaining our relationship as I was. I’m not re-evaluating what relationships mean to me because I’m unsure how to proceed now. I distanced myself from others too who were going in big trips and vacations abroad at the peak of the pandemic. I had to also move away from several covid deniers.”

Author wished to remain anonymous

“I’m so tired of being isolated. At least before covid, friends would visit, we had extended kin parties and dinners, and I felt the warmth and safety of having a community. I haven’t seen one of my partners since January 2020. Haven’t seen my parents or brother since December 2019. I am lonely, and adrift, and it’s so hard to stay connected to a world where I can’t connect with the ones I love.”

Blue
(they/them)
@cutecupcakeprince

“I think my family is sick of me. My partner is sick of me. No one touches me anymore. No one wants to hear it the catalog of ales and pains that debilitate me on a daily basis. This is standard though. The pandemic has only smushed us even closer together physically, and increased the spiritual gulf that separates us.”

Author wished to remain anonymous

“The pandemic destroyed my sexuality completely, being deeply connected to power and agency, it’s been very much at a loss. The stigma of bodies, both others and my own sick body has had complex emotional toll I know it will take years to work through and understand. The loss and grief in friendships has been tremendous. It’s been so hard to try to hold empathy and understanding while repeatedly being treated as subhuman as a high risk/immune fucked person. I’ve learned even people I thought to be some of my closest people have no idea how to show the kind of care I’ve always believed was the baseline and foundation of those relationships. The abandonment and betrayal feelings so many of us endure in pandemic times is tremendous.”

Author wished to remain anonymous
I don’t think my family will feel whole without my grandmother again. She was the matriarch of our family. We are still working to take care of each other, but it’s been really hard. We all live in different time zones and work or study on different schedules, which makes communication difficult. Some of us have health issues or are recovering from surgery. There are members of my family who are having difficulty processing her passing. We have other members of our extended family who are anti-vaxxers. Others are trying to make funeral arrangements, manage family life, and work full-time in frontline service jobs. It’s a lot of strain on the heartstrings, on top of all of this macro-level social stress.”

Author wished to remain anonymous

This has been the hardest part. When the vaccine was rolled out I watched my partner and most of everyone I know pretty much stop taking precautions. My partner started going out and gathering in crowds and large groups frequently without a mask. They exposed me to covid on my birthday and offered me no recognition of how their behavior had been reckless and inconsiderate towards me as I’d been disabled by covid. I left the relationship. My best friend of ten years who took care of me during the early days of long covid – we had to weather a lot of shit and the darkness of that period still leads to fights and trouble in our dynamic now. I became unable to care for myself in the most basic ways literally overnight, I had to rely on the able bodied people around me and they often didn’t understand how to support me. I didn’t have a large and varied support system when that happened.

This has been a huge source of grief.”

Author wished to remain anonymous

My partner and I are both disabled and immunocompromised. But we had been living with my folks at the start of the pandemic. When masks started being taken away, my folks quickly shed theirs. ‘They are so annoying’ they would say ‘and for what?’. My partner and I had to move out. They, in 2021, decided that the best way would be to go back to school masters. They got into a university in Colorado and we moved. But I’m bad at holding back and so I told my folks I was leaving because they couldn’t respect my disability. As a queer person, they claimed I piled too much on them at once and it was hard for them to adjust. I stopped feeling bad about that after 2 years though. By the time I left, it had been 5. My mom and I talk sometimes, my Dad apologized as I was leaving and continues to wear masks. Can’t remember the last time I talked to my sisters. But my partner and I are stuck together like glue. At least we have each other.”

Snow (they/them)
Chapter 3

“How DO YOU FEEL ABOUT "MOST" OF SOCIETY "REOPENING" AT THIS STAGE IN THE PANDEMIC?”


“Shut the whole thing down.”

Sarmistha Talukdar
(they/them)
@tavishi.experiments
Venmo: @Sarmistha-Talukdar
“i curl into the corner of the subway wearing an n95 on my way to my fourth doctor’s appointment of the week. i click through instagram stories of friends in clubs, friends in restaurants, friends celebrating ‘normal’ & flinch away when someone coughs in the waiting room. i’m laying in a hospital bed during pride weekend, feeling worlds away from clubs and parties and streets packed with maskless people, hot moving bodies & my iv drip is so cold in my arm. i don’t get to hold out on the statistics looking good, chances are not in my favor. i’m trying to swallow the bitterness of being left behind. i hope one day my world will be the same as theirs.”

venus
(they/them)
Twitter: @v1v1section
Venmo: @evyix

“Super anxious. I never loved the ‘normal’, I think a society in which the disabled, marginalized and historically excluded are an afterthought is a failed society.”

Meera Ghani
(she/her)
Twitter: @meeraghani

“I think it is too soon. I don’t think enough precautions have been kept in place to keep the most vulnerable safe. removing masks and allowing crowds to congregate in closed confined spaces has allowed for more infectious variants like Delta to spread and kill more people unnecessarily. They should have waited for at least 70-75% of society to be vaccinated before opening.”

Kyoko Heshiimu
(she/her)
Instagram: @dragonmomi8
Cashapp: $KyokoHeshiimu
Facebook: @ Eko Speaks Art

“this notion of ‘reopening’ is an illusion in order for capitalism, egos, and individualism to thrive. if we all wore masks, continued to social distance, kept in-person gatherings to a minimum, and followed protocols from the beginning, we would not have all of these variants and people continuing to die from this virus everyday (yes, people are STILL dying— did you all forget?). and, those dying are people who often don’t have the resources to stay safe. or, are suffering in isolation. this is just an ongoing nightmare while the able-bodied individualist world is continuing to have their parties.”

Author wished to remain anonymous
“Terrible. I tried to go back to physical society and the burnout was so bad I have been experiencing situational mutism and shutdowns/meltdowns for months after. Also terrible because of the blatant disregard of disabled people and also the movement away from Connecting online which has brought me and many disabled people comfort in these times. Online should be one norm, not just something that can be disregarded and forgotten”

Tai
(they)
@FelineForestMedicine
Venmo: @TaiCK
PayPal: PayPal.me/CranioWithTai
Zelle: 845.915.0798

“The government has money at it’s disposal to pay citizens to stay at home while we manage costs, but they won’t do it because of the greed. We are expendable as long as the money keeps flowing and we beg for another paltry $1,000. On the whole, disabled folks have been first to sacrifice on a consistent regular basis, and we’re so far in that people have simply accepted that people will get sick and die. It’s really disheartening and exemplifies how essential mutual aid efforts are to keep marginalized people safe and alive.”

Author wished to remain anonymous

“I am being eaten alive by terror every. Single. Day. I have doctors appointments I can’t miss or I will get much sicker or lose progress, and every time I have to be in public my heart is in my throat. When someone coughs it feels like ice gripping my lungs. My roommates work with the public and that scares me too, even though they take precautions almost no one does anymore. I feel sick when I see people without masks, at parties, or eating in restaurants. How can so many people not care about human lives? About my life, our lives, the lives of sick & disabled people and children who can’t get vaccinated? How can I believe that there are good people in the world, or that humanity is worth redeeming, when people actively choose death over inconvenience? The specter of death follows me at every step and how can I ever stop grieving when people are dying of a preventable illness because abled & well people don’t give a sh*t about anyone, even their parents, even their kids, even sometimes themselves.”

Blue
(they/them)
@cutecupcakeprince

“I am deeply saddened by the level of nonchalance that many seem to be affecting. I cannot believe how many Americans have chosen not to be vaccinated. There are countries begging for the vaccine and we are throwing it away in the trash. It is shameful.”

Author wished to remain anonymous
“People are in crisis fatigue, the imperfections and helplessness are raw and exposed. Individualism is fucking us all, racialized, working class, houseless, undocumented, disabled, struggling people especially. I see people giving up because they we’re never given consideration, and self centering out of exhaustion. I know the ethic of economy over people is to blame for the botched priorities of the state.”

Author wished to remain anonymous

“They yell and shout about how it’s their ‘personal freedom’, completely ignoring all of the people hurting and dying in their wake. Pure selfishness.”

Juniper Harwood
(it/its)
@howdyitsjunebug
Cashapp/Venmo: @queerphoria

“Anybody who is frequently gathering in large groups without a mask needs to recognize that they are hardly any better than people who won’t get vaccinated. If you’re going to clubs, traveling, gathering for parties without getting tested, or anything similar — you’re part of the problem. When the media and anyone else says its a pandemic of the unvaccinated this suggests they don’t give a fuck about children, immunocompromised people and all other high risk groups. I’m so sick of seeing the people in my life act above a virus that disabled me.”

Author wished to remain anonymous

“My brother told me that chronically ill and immuno compromised people should be locked up and everyone else should get to live a normal life. I guess he got what he wanted.”

Lavender
(They/Them)
Instagram: @therunawaygrunge
Twitter: @runawaygrunge
PayPal: PayPal.me/therunawaygrunge
Wealthsimple Cash: $runawaygrunge
Cash App: $runawaygrunge

“You can’t look at someone and tell they are disabled. You can’t. It is a disservice to the entire world to not wear a mask. I’ve been wearing masks since before the pandemic in public because of my condition. NO ONE had a problem with me until after the pandemic started. If I get sick, it means all my symptoms are cranked up to a ten as my body tries to fight the other thing going on and myself at the same time. It takes forever to “get better” leaving me bed ridden for weeks, sometimes months. Whatever normal you had before the pandemic was already my nightmare. We need to do better.”

Snow (they/them)
“Truly and deeply listen (not charity listen) to us (especially the most marginalized among us) for we hold the keys to a better, beautiful, abundant world, where no one is left behind.”

Sarmistha Talukdar
(they/them)
@tavish.ieperiments
Venmo : @Sarmistha-Talukdar
“To allow for remote working to stay accessible, to make events and meetings more blended (online and in person), to make healthcare universal, to pay caseworkers and what came to be known as essential workers living wages, to institute universal basic income, pay Black, indigenous and colonized people reparations, give their lands back and to TAX the rich.”

Meera Ghani
(she/her)
Twitter: @meeraghani

“Stop shaming people when they mask up. Keep your distance when asked.”

Kyoko Heshiimu
(She/her)
Instagram: @dragonmomi8
Cashapp: $KyokoHeshiimu
Facebook: @ Eko Speaks Art

“Prioritize sick people.

I have chronic pain, but I have to work through headaches and pain, and joint pain, and gut issues as I work in an office, taking public transportation. All of these things take a toll on me but I have no other option.

 Recognize that people do not have options and it’s an immense privilege to be planning trips and brunches and parties when folks don’t have their basic needs met on a consistent basis. Able bodied and healthy people need to be putting their money directly into the pockets of those in need, ensuring the moratorium does not expire, and providing safety and shelter for disabled/mentally ill/chronically ill people.”

Author wished to remain anonymous

“Wear masks, please don’t go out and party a lot, get tested a lot, make sure to wear your mask again anywhere around other people...and keep on advocating for online spaces, in your work, school, community, etc. Ask your friends their preferred method of communication. Let’s work toward being less ableist toward each other as a whole.”

Tai
(they)
@FelineForestMedicine
Venmo: @TaiCK
PayPal: PayPal.me/CranioWithTai
Zelle: 845.915.0798
“If you are able to (if you do not have a health reason that is preventing you to do so), please continue to WEAR YOUR MASK!

If you do not have to, PLEASE STOP TRAVELLING. Can you all please just sit still? Lie down? How about some solidarity with bed-bound and home-bound folx? Maybe just this once? Like, is that too much to ask?

Please also stop travelling to places where they also have their case numbers low or under control. Like, how are we protecting our fellow people who are also globally compromised in this pandemic?

Please think about how you live and are in collective relationship with other people outside of what ableism, capitalism, and individualism tells you to do. PLEASE.”

Author wished to remain anonymous

“Get vaccinated. It’s free & it protects you and your community! Be cautious, wear a mask, assume there are always vulnerable people around because we are everywhere. If you’re not doing these things, know that we see you, and your actions speak loudly. We know you aren’t safe, & that you don’t care if we live or die.”

Blue (they/them)
@cutecupcakeprince

“Continue to be as flexible as you became during the great quarantine. All of a sudden, those doctor appointments that took me hours to build up energy for and cause me intense pain and hours of recovery time afterwards could be done on my phone! Astonishing! Suddenly now, that flexibility is disappearing and we are back to requiring enormous sacrifice for disabled and chronically ill people just to make it to a doctor’s appointment so they can get my blood pressure and my weight in person.”

Author wished to remain anonymous

“Like all experiences, the pandemic is a teacher. The lesson it’s carrying is crucial and urgent. It seeks to teach us that we are inherently interconnected beings. On a literal physical level we are dependent on one and other. We need to learn now, or too late that we are more than our physical selves and that we have responsibility to each other. There is so much beauty, power and remediation to be had in this lesson and I believe it is key to moving forward.”

Author wished to remain anonymous

“Get your shots. Do it for her. Do it for your parents, your grandparents, for everyone that couldn’t. It’s a pinch. Grief hurts more.”

Author wished to remain anonymous
“COVID is worse than it’s ever been in most places, likely than it’s ever been. If you are not acting just as careful as you did when the pandemic started and you were scared as hell, then you’re not reacting appropriately. This isn’t the time to go to parties, festivals, or on vacation.”

Juniper Harwood
(it/its)
@howdyitsjunebug
Cashapp/Venmo: @queerphoria

“Ask your disabled and chronically ill friends if they want a meal. Send them 20$ for seamless or cook for them. Offer to do shopping or chores for them. Its been the single most frustrating experience of my life to struggle to meet my most basic needs and see that abled people around me are so clueless as to how to help me when its as simple as helping me out with a meal. Just ask us what we need. Stop offering unsolicited medical advice, we’ve likely heard and tried it all. Stop trying to fix us or the conditions in our life and ask us how we need help. We know best what help we need; don’t come in with preconceptions and then feel rejected when we tell you we need help in a different way. We know best what our needs are. I’ve personally only wanted my friends to listen more and ask me what my needs are.”

Author wished to remain anonymous

“You’re killing people like me every day. You’re ensuring that full service sex workers (many of whom are chronically ill or disabled) either can’t work, transition to a whole new style of self employment (which requires internet access and privacy), or to risk their lives to make a living. You’re keeping people trapped in their homes because a drink with friends is more important to you than our lives. Shame on you.”

Lavender
(They/Them)
Instagram: @therunawaygrunge
Twitter: @runawaygrunge
PayPal: Paypal.me/therunawaygrunge
Wealthsimple Cash: $runawaygrunge
Cash App: $runawaygrunge

“You want normal, I want to live. There’s a significant difference between those two things. Please recognize every time I go into public I am scared. I have a cane, a mask, am openly trans, and am sometimes with one or more of my partners. I am scared not because of stories but because of lived experiences. I’ve been yelled at for wearing a mask, yelled at for having a cane “as a young person”; I’ve had my mobility devices broken by people who shrug it off as an accident, I don’t want to be afraid to live! I don’t want to be afraid...”

Snow (they/them)
WHAT WOULD YOU LIKE TO DEMAND FROM YOUR FRIENDS, FAMILY, COMMUNITY, AND/OR SOCIETY RIGHT NOW?

“to keep wearing their masks, get vaccinated, help others get vaccinate (if there is no public vaccine available), push for a #peoplesvaccine, dismantle capitalism!!”

Meera Ghani
(she/her)
Twitter: @meeraghani
“Please get vaccinated and stop feeling offended if you are asked to mask up even after you have been vaccinated. I have been vaccinated since February/March but I still mask up because I am still vulnerable. 95% is not 100% and I can’t risk it right now. Be loving and caring. The level of worry I have about my health is scary and I want to be the least invasive to your life while still being included in society.”

Kyoko Heshiimu
(She/her)
Instagram: @dragonmomi8
Cashapp: $KyokoHeshiimu
Facebook: @ Eko Speaks Art

“Care > self-centered wishes. Please…if we have learned anything from this it’s that we need to care about each other, we are not separate in many ways. I know you want to go out and socialize, but…please, consider that that could be at the cost of someone’s life indirectly.”

Tai
(they)
@FelineForestMedicine
Venmo: @TaiCK
PayPal: PayPal.me/CranioWithTai
Zelle: 845.915.0798

“The absolute biggest demand I have always had is for my health insurance. FUND MY TREATMENTS. Fund preventive care so I don’t need ER visits and unplanned crises! Help me function, instead of waiting for me to fall apart and then tape me back together! Provide funding for daily healthy living, instead of throwing more pills at me.”

Author wished to remain anonymous

“Disabled and sick people hold so much value, and deserve to be at the forefront of a lot of conversations happening right now. We’ve been treated as completely disposable during this pandemic, more than usual, and it’s time to listen.”

Juniper Harwood
(it/its)
@howdyitsjunebug
Cashapp/Venmo: @queerphoria

“The bare minimum is masks and vaccines. The next step is creating access for others and ensuring that the rest of us can at least leave our homes without literally fearing for our lives.”

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DO YOU HAVE AN AFFIRMATION YOU WOULD LIKE TO SHARE WITH OUR COMMUNITY?

"Your love and vision is what makes the world go round"

Sarmistha Talukdar
(they/them)
@tavishi.experiments
Venmo: @Sarmistha-Talukdar
“You are not alone, we are in community, we need to keep speaking up and taking up space!”

Meera Ghani
(she/her)
Twitter: @meeraghani

“We will get through this together”

Kyoko Heshiimu
(she/her)
Instagram: @dragonmom8
Cashapp: $KyokoHeshiimu
Facebook: @ Eko Speaks Art

“I’m with you. In your lonely moments. In your moments where you think you couldn’t get lonelier, couldn’t be more misunderstood. When all you want is someone to take care of you, ask you about how you’re doing. I’m with you in that. Let’s be held within each other’s wishes, even if from afar. You’re not alone—or maybe we are, but We are Alone Together...even across distances...we are still on this planet at the same moment in time. I’m with you.”

Tai
(they)
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Zelle: 845.915.0798

“I would give all of you a hug if I could.”

Author wished to remain anonymous

“You are worthy. Your life matters. You matter. The people that don’t see that are not worth your precious time or energy.”

Blue
(they/them)
@cutecupcakeprince

“Your pain, confusion, anger and disillusionment is real. It’s okay to be imperfect, believe yourself.”

Author wished to remain anonymous

“I’m not sure where to start, because we’re all feeling a lot of feelings right now, and a lot of them are negative and weigh us down greatly. There is love, support and hope within our community. We care for each other in a way I’ve never known anywhere else. We’ve got us when no one else does. I love you all like family.”

Juniper Harwood
(it/its)
@howdyitsjunebug
Cashapp/Venmo: @queerphoria
“Your needs aren’t too great just because people in your life weren’t able to meet them!”

Author wished to remain anonymous

“You are a magical being. You endure things these other people could only imagine, and who cares if you do it with grace. Be loud, complain, ask for the things you need. Don’t take less.”

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(They/Them)
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Wealthsimple Cash: $runawaygrunge
Cash App: $runawaygrunge

“You are worthy or respect. You are worthy of life. You deserve more than this world can ever give you. You are beautiful. You are kind. Most importantly, you are you. Never let anyone tell you how you are supposed to live your life. Never let anyone stop you from finding joy.”

Snow (they/them)
"My dream world of accessibility is where everyone, be it any disability or sickness is able to feel valued, included, cared for and have the tools and support to be the selves that they desire and imagine to be."

Sarmistha Talukdar
(they/them)
@tavishi.experiments
Venmo: @Sarmistha-Talukdar
“A world where people can be themselves without being judged or abandoned. People support each other, we have thriving communities where people have the power to decide how to run their own neighborhoods, there is affordable housing, free public transport, universal health care, people don’t have to work to the bone to have their needs met because everyone get UBI, and the taxes that people pay on what they earn from their work is used to coordinate across regions focus by that’s what those representing them at the local and regional councils. There’s free childcare, and other care facilities, education and access to internet. We don’t have prisons because people can come together as community to hold those who cause harm accountable and provide support to those who have been harmed. People understand that the mind, body and spirit are all connected and that we are all interdependent and a part of a collective....hence the focus is our interbeing.”

Meera Ghani
(she/her)
Twitter: @meeraghani

“I want to be able to go to the river. It is so hard to access nature now that I can’t walk far. Walking requires so much of my attention, and I have to go so slowly, and look at my feet while I walk. But even more than that, it’s most of the time not even feasible for me to get to a nature path. I want to be able to get so close to the river that I could put my hand in it. I want a path there that a wheelchair could go on. That’s my biggest dream – don’t force me to be disconnected by building paths I can’t travel.”

Author wished to remain anonymous

“Celebrating differences rather than being afraid of them. Normalizing variability and biodiversity. Interacting with other species. Group rituals/connecting.”

Tai
(they)
@FelineForestMedicine
Venmo: @TaiCK
PayPal: PayPal.me/CranioWithTai
Zelle: 845.915.0798

“Shut down any businesses that aren’t accessible. Total shut down of anything and everything that is not accessible for able bodied and able minded folks to rally understand that the world they live in is tailored to only them. Remote work and remote school as ideal options that have a great idea of funding. Dismantling of the restrictions for disability and SSI, regular consistent funds and medical care for anything disabled folks need.”

Author wished to remain anonymous
“When designing new buildings and spaces and planning events the first conversation will be “how can we make this accessible to the most marginalized members of our community”. Accessibility is a forethought. Sex work is presented as a viable emotional option for disabled and chronically ill people.”

Lavender
(They/Them)
Instagram: @therunawaygrunge
Twitter: @runawaygrunge
PayPal: Paypal.me/therunawaygrunge
Wealthsimple Cash: $runawaygrunge
Cash App: $runawaygrunge

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Author Information

DISTORIES

DISTORIES is a small open-source and open-access Instagram zine project, gathering testimonies from disabled contributors. The project was stewarded by geunsaeng ahn from September 2021 to July 2022. Sixteen anonymous and named individuals have contributed content to this excerpt. Identities listed in the section just preceding the chapter excerpts are from all sixteen authors’ own descriptions of their identities from submissions, as of July 2022. For those authors who did not choose to remain anonymous, readers will find information such as names or monikers, social media handles, and payment platform handles/accounts under each contribution, in each section. Some handles may not currently work, though they were active at the time that contributors shared them with DISTORIES.
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