

# Our Resistance: Stories of Disability Rights Activists

Documenting Disability Rights activists' stories of resistance is a deeply political act. This feminist storytelling project tells the beautiful, rich, diverse and unfiltered stories of Anisie Byukusenge, Aminata, Crystal Asige, Elizabeth Patricia Pérez, Estefanía Cubillos Nova, Indira Azucena Vargas, Mariana Veliz Matijasevi, Nur Matta, and Monica Yeanie Ghaliwa: nine Disability Rights activists working to transform and remake the world.

Seeded and curated by Purposeful, a feminist hub for girls activism, rooted in Africa and working all around the world, in partnership with Stories of Girls' Resistance, a global feminist storytelling project dedicated to documenting and amplifying the invisible and untold stories of girls, women, and non-binary people's resistance.

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## OUR RESISTANCE: STORIES OF DISABILITY RIGHTS ACTIVISTS

*To resist is to take space, transform, and persist  
To smash what has been pushed as the bounds of permissible  
To care and sustain each other,  
rooting our individual and collective dreams as the compass of the reality we create and seek  
To resist is to honour our stories, journeys, and experiences  
Understanding that each act of resistance is  
sparking, powering, and sustaining transformation  
Healing ourselves  
Healing each other<sup>1</sup>*

Stories capture our individual and collective realities, they are the fabric of our shared experiences. Yet, the stories of girls and young people – especially those with disabilities – have been and continue to be erased and ignored; most often told from the perspective of another person and in a tokenising and paternalistic light of “inspiration” or pity. By erasing the full humanity, richness, diversity, and multidimensionality of people with disabilities, society stigmatises, generalises, and stereotypes the community at large, which consciously and unconsciously furthers violence and injustices. And it overlooks the power of the community with disabilities and its culture. As Alice Wong, a Disability Rights activist, writer and founder of the Disability Visibility Project shares: “...disability is not a monolith, nor is it a clear-cut binary of disabled and non-disabled. Disability is both apparent and non apparent. Disability is pain, struggle, brilliance, abundance and joy. Disability is socio-political, cultural, and biological. Being visible and claiming a disabled identity brings risks as much as it brings pride.”

Documenting Disability Rights activists’ stories of resistance is a deeply political act. Introducing *Our Resistance: Stories of Disability Rights Activists*, a feminist storytelling project that tells the beautiful, rich, diverse and unfiltered stories of Anisie Byukusenge, Aminata, Crystal Asige, Elizabeth Patricia Pérez, Estefanía Cubillos Nova, Indira Azucena Vargas, Mariana Veliz Matijasevi, Nur Matta, and Monica Yeanie Ghaliwa: nine Disability Rights activists working to transform and remake the world into one that honours their full and rich humanity, experiences, and that is rooted in Disability Justice. This storytelling effort was seeded and curated in partnership with *Stories of Girls’ Resistance*, a global feminist storytelling project dedicated to documenting and amplifying the invisible and untold stories of girls, women, and non-binary people’s resistance.

These stories of resistance use a *political poetic narrative* style that weaves the resistance story of activists in their own words to capture and honour their journey, experiences, activism, the people and communities that have contributed to their story, and life lessons. Poetic narrative is an ancestral oral practice that has existed for hundreds of years, across territories and cultures. It is a powerful way to document, share, and preserve life, wisdom, experiences,

<sup>1</sup> Poem by Laura Vergara - Inspired by the resistance stories

reflections, and build community. *Political poetic narrative* is rooted in the understanding that one's identities and context are political and inherently connected to one's resistance to systemic oppressions and injustices.

## **NARRATIVES MATTER, NARRATIVES SHAPE OUR WORLD**

As an organisation, we understand the impact that language has in shaping narratives and our understanding of ourselves, each other, and the world. We want to begin this offering by recognising that when talking about disabilities, there is a rich and wide diversity mirroring the diversity in disabilities themselves. We do not believe in a one size-fits-all approach, but rather being in continuous conversation to understand how we can co-create narratives that honour and respect individual and collective experiences. And through this process of co-creation, re-shape our understanding of our world.

We invite you to read [\*Resourcing Disability Justice: Feminist Journey Toward Centring Disability Justice\*](#) to dive deeper into the set of guiding principles that we created in conversation with Disability Rights activists, artists, organisations and funders, to guide our efforts to honour the stories, experiences, and intersecting identities of people with disabilities. We are in a continuous process of learning and unlearning and are deeply grateful to the Disability Rights movements and individuals powering it, and those who have led the way throughout history to break the bounds of what has been drawn as permissible by an oppressive system to create a world that is not only more accessible, but where we all belong.

# Anisie Byukusenge

## Kigali, Rwanda

***“I have a dream that one day we will all have access to opportunities regardless of disability, regardless of ethnicity, race, religion, sexual orientation, regardless of anything. Inequalities are the source of every struggle”***

Anisie is a youth and Disability Rights activist from Rwanda. She holds a bachelor’s degree in translation and interpretation. She is talented in poetry and her poems have been awarded and recognised in festivals both nationally and internationally. Anisie is a youth activist who advocates for empowerment, inclusivity and better access to services for persons with disabilities. She has worked with organisations focused on people with disabilities such as Umuryango Nyarwanda w’Abagore Bafite Ubumuga (U.N.A.B.U. – the Rwandan Organization of Women with Disability) and UWEZO, an initiative that aims to improve competencies in literacy and numeracy among children. Currently, she is a Programmes Assistant at Purposefu.

Through her poetic-political narrative, Anisie shares the pain of her childhood caused by a society that stigmatised and isolated her. Through her poetry, she explores her journey of healing, discovering the world, finding joy, and is able to embrace her story. Anisie’s narrative centres the power of people with disabilities and the importance of supporting each other, breaking barriers, and understanding each other’s struggles. As she wisely shared, resistance is her healing.

### ***What Have I Done Wrong, Mother Nature?<sup>2</sup>***

*The path of acceptance goes with the experience of rejection  
Everyone I tried to touch, just pushed me away  
Everything I try to hold on, goes away and I fall  
I thought I was born with bad blood  
But I didn’t stop  
I went to start with Primary,  
And continued with Secondary  
Now see, I’ve finished University  
But trouble: Never come! Never stay  
In that trouble that came to me,  
I’ve seen the good and the bad sides of humans...  
In conversation with God, the creator:  
Now, I come toward you.  
To give you all my sorrows.  
I’ve come so you teach*

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<sup>2</sup>Excerpt from Anisie’s poem.

*How to accept and be grateful of how you created me  
See, there is no kindness beyond that  
Teach your creatures not to be against me  
How you created me*

*I wrote this poem to tell my story.  
The story of having to fight to stay alive, get an education, and go outside.  
Experiencing the world, when the world is shut down, is hard.  
I suffered from depression, oh I prayed to God.  
I realised that my blindness affected me, because society rejected me.*

*I began losing my sight when I was six months old,  
and I completely lost it when I was five years old.  
I was angry,  
very aggressive.  
In Rwanda, where I was born, people would say that our family had a cast,  
because they had a child who was visually impaired.  
I was very intelligent but very shy.  
I felt I could not contribute to society,  
a sign of depression.*

*I could not see the world,  
not because of my disability, but because I was kept home.  
I was kept home to protect me.  
My mother would fear that the world would hurt me,  
that I would be raped,  
that I would face difficulties.  
This led me to feel weak, isolated and ashamed.  
By the time I was seven, I wanted to commit suicide.  
My childhood was really weird,  
It was really hard,  
especially because society was not on my side.*

*Fortunately, things changed.  
I began to experience the world,  
to break the barriers.  
And, through poetry, tell my story,  
and teach society.  
By breaking free, I was healing myself,  
and healing others.*

*When I was 14, I escaped home.  
By the time I was 16, I was travelling.  
With my boyfriend and cousin, we experienced beautiful things,  
I was enjoying the world,  
I was learning to love life.*

*After losing my sight, I was prohibited to swim.  
The constant fears and assumptions that kept me from experiencing the world.*

*Yet, I went with my boyfriend to swim.  
It was one of the most beautiful moments,  
I will never forget it, it was like a paradise.  
I was in the water,  
Going right,  
Left,  
Up,  
And down.  
I felt fear, but let it flow.  
I felt joy and soaked that.  
I felt that like water,  
I can be fluid,  
supporting,  
healing,  
and nourishing.  
Even if I felt the fear.  
I was enjoying the world,  
I was learning to love life.*

*I keep loving life.  
I keep going.  
I keep trying.  
I continued to use my poetry to share my story.  
I have gone to Glasgow, Scotland, and many more.  
Going in front of many people to give them messages to fight against disability injustices.  
An advocate using my power.  
This is resistance.  
By healing myself,  
I am healing others.*

*I compare my past, my childhood, to my present,  
totally different.  
I can't use my eyes, but I didn't lose my vision cause I can really see,  
there's nothing I can't achieve.  
I still have to do more,  
But, I can describe myself as successful.  
I graduated from university,  
I support my family, my community, my colleagues.  
Giving up is not in my vocabulary,  
I am courageous.*

*I realised that each and every person has their struggle.  
I realised that life is a gift.  
I realised that I could not really rely on people who did not prioritise my impact,  
or who thought that I can't do anything,  
that I would not be able to reach anywhere,  
who thought that I could not contribute.  
I reject it,  
I keep going.  
I focus on the people who really trust me,*

*my competence.  
This is resistance.*

*That's why I wish that young girls with disabilities do not let anyone discourage you.  
Don't allow them to spoil your dreams.  
Keep going.  
We are together in this battle.  
If you have one voice, you may feel ignored.  
But when you are with other people, you feel motivated and strong.  
Each and every person can be a partner in our life journey of changing and teaching society,  
of breaking the barriers, and the stigma.*

*Even today, people don't really understand,  
put much effort or try to learn about our competence and capabilities.  
We have a lot of potential.  
We contribute to society.  
Why do I really need to continue to say big please include me, please think about.  
It is really unfair that up to now, we're still having to beg for our rights,  
we are human beings.  
Remember that every human must have full enjoyment of their human rights,  
it is mandatory.  
So it is not a favour.  
We have a right to eat,  
to leisure,  
to education,  
to every right.*

*I have a dream that one day we will all have access to opportunities regardless of disability,  
regardless of ethnicity, race, religion, sexual orientation, regardless of anything. Inequalities are  
the source of every struggle. So this is not only for our own interest. This is also for your own  
interest.  
I feel that we must support each other in our struggles, because if I had stayed in the situation of  
being ignored and not having access to education, if I remained in that, no one would really  
know my name.  
So every night, before I sleep, I think about my day and ask: how did I really contribute to the  
change?  
And, until we reach the society that I dream,  
I will keep raising my voice.  
I will keep dreaming.  
This is resistance.*

# Aminata<sup>3</sup>

## Makeni, Sierra Leone

***“I have learnt that women have many rights. I have learnt that there is ability in disability. Our mentor taught us that disabled people have rights, that we should be bold to demand our rights because we deserve to be respected in our community.”***

Aminata is a young Disability Rights activist in her community in Sierra Leone and a member of a vibrant girls' collective. She advocates for people with disabilities, challenges the harassment and abuse they face and demands action from community leaders. Aminata's actions have resulted in passing a law in her community, an action that now protects everyone with a disability in her community from harassment and abuse.

*People were mocking our children in school because they have disabled parents. I was worried this would derail my child from acquiring education. I had to make my report to the Director of the Camp where we live. I told him not only about what happened to my children, but also about our rights as disabled people to be free from this mocking in our community. The Director summoned the entire Community to address this behaviour.*

*I was given the opportunity to talk and I said to everyone there that their children are mocking our children and their parents aren't doing anything about it. The Director implored the Chief to make laws against such behaviour. That meeting put an end to that ugly behaviour and it doesn't continue any more.*

*Now the community involves us in any community undertakings. We were informed about plans to construct a road and we made our inputs which were endorsed. Formerly, they looked at us as idlers and we had to tell them that they may not understand the seriousness of what we are about because they are not involved. Today, I am feeling good and respected in my community.*

*Aminata's story was part of the Girls' Circle Collective, Inside the Circle report. As a girl with a disability, Aminata shares how a life of discrimination caused her to lose sight of her own value, leading to a life of isolation and vulnerability. A mentor, seeing Aminata begging, invited her to join a Girls' Circle. This mentor's action transformed Aminata's life. Leaning into her voice and power, Aminata went on to challenge discrimination against all people with disabilities in her community, leading to community by-law protecting people with disabilities from harassment and abuse. Her actions have opened up decision-making platforms to her and her friends.*

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<sup>3</sup> As requested by the activist, a pseudonym/alias was used.

# Crystal Asige

Mombasa, Kenya

***“Liberation to me looks like independence. Not having to beg, or to convince somebody of my worthiness or anything like that. Just being able to wake up in the morning and be independent. Do what I've been created to be: Everything.”***

Crystal Asige is a Kenyan award-winning singer-songwriter, public speaker, human rights defender, and feminist activist. She works to tackle issues prevalent in the disabled community and offers leadership in writing petitions to relevant institutions and policymakers and presenting matters concerning the intersectionalities amongst visually impaired people. She founded the first visually impaired person support group in Mombasa, is an Amnesty International Board Member, and has received multiple awards for her music and activism.

Through her poetic-political narrative, Crystal honors her African culture, her Luo heritage, and pride in her disability. She shares her continuous resistance against being shut down, abused, and stigmatised – celebrating being her most authentic self. And how she walks, step by step, with faith, learning, unlearning, exploring, and using her powerful voice to break barriers and resist. This narrative exposes the stigmatisation, violence, shame, and discrimination experienced by people with disabilities at the intersection of race and gender. Yet, despite the context, the power of her resistance and faith supported herself and community – as Crystal shares: “ a rising tide lifts all boats.”

*I believe that the sun doesn't use its own rays,  
it is there so that it can light other places.  
I believe that a river doesn't drink its own water,  
it's there to provide water for others.  
I believe that a tree doesn't grow fruit for its own sake,  
It grows fruit so that others get nutrients from it.  
We're not just here for our own,  
We're here for our community as much as the community is here for us.  
That's the African culture, isn't it?  
We know that a rising tide lifts all boats.*

*I grew up in Mombasa.  
My heritage is Luo.  
I lived a very normal childhood.  
I was happy, curious, independent, I never used to follow the crowd.  
When I was 5, a man touched my shoulder,  
something did not feel right,  
I stopped him,  
I demanded my space.  
I was assertive.  
I began my resistance.  
I resisted in school by continuing to speak in Swahili,  
English was being pushed as the national language,*

*but if I'm talking to my friend, I wanted to express in Swahili.  
It apparently made me disobedient.  
Even though I'm Kenyan,  
Swahili is Kenyan.  
English came with colonialism,  
language is very important,  
removing language is removing culture.*

*I've always been an underdog.  
Somebody who people don't really believe in,  
before going to university, I moved to an international school.  
I was teased for my Afro hair.  
I was teased for my accent.*

*I was very into drama, theatre, poetry, recital, the arts.  
I would be on the stage a lot and I would have to rehearse.  
When I was I around 14, I began to have trouble reading my scripts,  
as the years went by 15, 16, 17 years old, it became worse and worse.  
I went to the doctor; they gave me some eyedrops and sent me home.  
Then in the University in UK, I went for a normal checkup,  
the doctor said: "Hey, crystal, I don't mean to alarm you, but something is wrong with your  
eyesight."  
I learned that I had glaucoma,  
my life changed basically from there on.*

*I went through depression.  
I was trying to finish my studies at the same time I was alone.  
I remember not telling my parents immediately,  
cause I just knew that they'd be worrying back in Mombasa.  
They had sent their child to the UK,  
thinking this is the beginning of her life, opportunities.  
All of the sacrifices for me, all the money  
I lost sight of who I was.*

*It was very draining.  
I was trying to figure who is Crystal with a disability?  
I came home after I finished university.  
Trying to rehabilitate now with my new life  
I felt a lot of embarrassment and shame.  
Humans need to create our own belief system,  
challenge God.  
I began to do that,  
I would say that was a milestone moment.*

*I put power back into my disability.  
When I was labelled as disabled, it sounds very negative.  
So I labelled myself V.I.P for visually impaired person,  
it gives me the power back.  
I feel confident.  
Having a disability is not a bad thing,  
It's something that you can actually take and flip it around and make it work for you.*

*I named my white cane Faith.  
We walk by faith and not by sight.  
Faith became my life, my reality.  
I never leave home without Faith.  
I always make sure that Faith is close to me.  
I always make sure that I am extending Faith.  
Every time I open my white cane,  
I'm extending my Faith.  
I'm putting faith in front of me.  
Every footstep 1, 2, 3, 4,  
I'm always with Faith.*

*Today, home is Mombasa and Nairobi.  
I'm blessed, powerful, resilient, funny.  
I am loved.  
I'm happy for all the experiences,  
all of the challenges, ups, and downs.  
At the end of the day, it's like sculpting,  
each chisel slowly makes a beautiful sculpture  
I feel like that's my life.*

*Discrimination has been a big part of my life.  
It's been very disheartening that people are judged and discriminated against who they are.  
I go into the interview room with faith and the tone changes.  
It is always heartbreaking.  
One glance and they already made up their mind about me.  
Not even knowing who I am,  
not understanding what I can do.*

*Sexual harassment has been a big part of my life as well.  
Once he realised I was blind,  
He tried to push me inside the back of the car,  
I screamed,  
I reported it to the police station,  
he was called in.  
Then the man told the cop: "I was trying to help her"  
That's how he turned the story around.  
And because it was a man talking to another man,  
they were just like: "it's a misunderstanding, Madam"*

*My disability has made people disappear from my life.*

*You know, maybe associating with me was not cool.  
So, I don't have that many friends,  
but the friends who I do have are the real deal.  
I enjoyed that my disability helped filter out the people who are not supposed to be in my life.*

*I love socialising, dancing, yoga.  
I love being in the water, road trips.  
I love learning and meeting diverse people.  
I want to impact more, influence, change people's minds,  
basically, break the glass ceiling.  
The sky is no longer the limit, it's even further*

*I started therapy in 2020.  
I've been working through those kinds of things,  
childhood traumas,  
trying to reprogram so I can be the best version of me.  
Unpacking whatever was holding me back.  
I have been fortunate to meet many people who support me,  
they are just like superstars basically.  
They taught me a lot and helped me unlearn what I used to think was true.*

*In 2003, there was a disability act that was passed.  
I didn't acknowledge it, because I was still a teenager.  
It now translated in many of us being empowered,  
helping more understand our rights as people with disabilities.  
Even though there's still a long way to go,  
it was quite progressive,  
not many other countries have any laws regarding people with disabilities specifically.  
Disability should be a priority.*

*Music is a really good way to go around and to get your point across,  
to give people a message.  
I will always use my voice to speak, and resist.  
In my video there's a person in a wheelchair,  
there's a deaf person,  
they are real people with disabilities,  
the way I am a real person with a disability.  
We create resistance against traditional media.  
People expect me to always wear sunglasses,  
they hold the stereotypes.  
I try to demystify or debunk them with my music.  
Cause I'm disabled doesn't mean that I want to cover up.  
I want a miniskirt and I want to dance.*

*I'm a human being.*

*I have faced being blacklisted,  
as they say: "that girl is problematic,  
she talks too much.  
She's too loud."  
I'm glad that I resisted.  
I believe that if I just keep pushing,  
something will have to shift.  
My faith has been strong,  
it keeps me grounded,  
keeps me going.*

*We need to work at the intersections,  
because one thing affects another.  
Most of the time our struggles are never appreciated.  
People holding your hand,  
people walking with you,  
people seeing you,  
hearing you,  
that's solidarity.*

*Liberation to me looks like independence.  
Not having to beg,  
or to convince somebody of my worthiness or anything like that.  
Just being able to wake up in the morning and be independent.  
Do what I've been created to be: Everything.*

*I was told I couldn't run, so now I fly  
Told I shouldn't argue, but my spirit fights  
Told I couldn't drive, now I'm flown  
Told I'd never work again, look at all I've done.<sup>4</sup>*

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<sup>4</sup> Excerpt from [Crystal's song Ninajijua](#)

# Elizabeth Patricia Pérez

## Chiapas, Mexico

***“We hierarchise the differences to see who can do more than the other. And those who can't, we minimise them, we exclude them. We don't see that these differences are complementarity. That is structural violence.”***

Elizabeth Patricia Pérez (Eli) is an Indigenous feminist Mexican Disability Rights activist and human rights defender that works as a writer and community organiser. She is the President of Amor Sin Fronteras and part of the National Feminist Disability Network in Mexico (Red Femidisca). She has written multiple articles about disability at the intersection of gender, social movements, politics, love, family, and COVID.

Through her poetic-political narrative, Eli shares her journey of breaking from the binaries in life, not everything is white, not everything is black. She honours her journey to sustain and fight for herself, claiming her power and her freedom. And highlights the support she has provided and has received from her community, creating “shared resilience.” This narrative exposes the painful violence of an ableist world, and the empathy, joy, laughter and growth that exists, resists, and flourishes – expanding minds and opening hearts.

*A panda,  
not everything is black, not everything is white,  
as contradictory as life.  
These colours for me represent strength,  
vulnerability,  
our light and shadows.*

*Strength and vulnerability,  
Are important components in every movement,  
for every person.*

*A panda, or as I called it: pachoncito,  
meant a lot of sisterhood,  
a lot of empathy.*

*Not everything is black, not everything is white.  
Since I was a child, I started to realise it:  
my life was not just hospitals,  
I also had joy.  
The panda bear reminds me of my dad,  
a visit to Mexico City,  
the Chapultepec Zoo,  
Oh, the panda bears!  
At that time I was able to see.*

*I also remember an economic crisis.  
On my birthday my dad said:*

*"I can't buy you the big gifts;  
but I have this for you."  
It was a little panda bear,  
I kept it forever.*

*I have been in hospitals since I was a child.  
Whenever I felt like I couldn't anymore,  
My dad would say to me: "everything is going to be fine."  
I have held to that saying.  
Life itself has led me to understand  
that everything is going to be fine.  
From where I am in life right now,  
my strength,  
those of my ancestors,  
and of my parents,  
in spite of the struggles of my family,  
today I am grateful of their ways,  
they pushed me.*

*My strength has also taught me to defend myself,  
being the only female of four siblings.  
Being able to use my strength to defend myself has also played in other scenarios:  
fighting for my education,  
and Labour.  
My strength is my voice,  
defending myself,  
because no one can describe what I have experienced.*

*Our voice is our strength,  
no one better than ourselves understands what we have lived,  
and we must be part of the spaces to put our experiences on the table.*

*My voice is always present when faced with situations of violence,  
Within me, I listen:  
"Eli, you can get out of this.  
You can grab your cane and get out of this situation."*

*My inner voice says: "you can do it."  
It is always there,  
there is always doubt,  
uncertainty.  
And, at the same time that courage.  
This inner voice also tells me:  
"this moment is going to pass."  
This voice helps me,  
reminds me to breathe.  
Breathing in the sense of  
"I am alive,  
this is going to pass  
and I will find the tools to overcome what I am going through".*

*I also believe in the power of support networks,  
in those other voices that have accompanied me along the way.  
Without those other voices,  
we cannot know ourselves,  
we cannot see for ourselves.  
We need one another,  
we sustain each other.*

*In our case, for those who have a disability,  
it's not easy to get out there,  
to live in a system made to exclude us,  
in a world where our rights are violated,  
where there is barely any space for us to learn and be together.*

*Today in the morning I remembered a song  
"Breaking through, overcoming fear."  
by Paulina Goto.  
I remembered freedom,  
the freedom we are looking for,  
freedom for all women living with any type of disability,  
my own inner freedom that I seek on a daily basis,  
to break my own fears,  
learned fears,  
break the taboos that encapsulate us,  
that try to contain us.*

*Freedom,  
I was always unknowingly looking for her;  
five years ago I started training in sexuality,  
and it dawned on me:  
What has happened to me that I do not dare to live my full self, exploring other parts of who I  
am? From other experiences?*

*Social structure, and family implicitly told me:  
"you can't."  
"you can't live yourself from your body,  
you can't live your sexuality,  
you can't go out on the street alone,  
you can't."*

*I'm starting to get the hang of it,  
that I have a body,  
my own sensations.  
That I am allowed to feel,  
to be free!*

*When I write my autobiography,  
reflecting on what have I done with my life,  
I have done things that contribute to society  
but...on the personal side:  
I have yet to turn around and see myself;*

*To connect with that inner freedom,  
the one that makes me challenge my fears,  
letting go of the:  
"don't wear that"  
"don't come out with that."*

*The freedom to live in my body has come from the wisdom of teachers, allies, colleagues,  
and myself.  
We have learned how to overcome it,  
learned that we are not the only ones,  
learned that there are other ways of being,  
other ways of living.  
Life is trial and error.  
We are all full and rich bodies,  
I have my body,  
I inhabit my body,  
it is my body,  
and I have full autonomy over my body.*

*With my body,  
I had to learn to use a white cane,  
allowed myself to explore,  
leave the house,  
walking the obstacles on the streets,  
Life.  
And, in the absence of my eyes,  
I developed listening skills,  
touch,  
connecting with myself,  
And how to reach out and ask for the support I need.  
my feet have learned to feel what my eyes no longer see.  
Feel from my skin.*

*And from my activism,  
In Femidiscas,  
a network that emerges because of the pandemic,  
a group of powerful women from different parts of Mexico,  
connected to question and explore the world,  
focusing on gender perspectives,  
inclusion,  
And, what it all means?*

*At our first meeting,  
it was shocking to learn that I was not the only one.  
To connect with this collective of us by us.  
To have a rooting of non-judgement,  
to respect our time,  
our feelings,  
And understand that activism has many approaches, and all are valid and valued,  
for us is cyberactivism.*

*The spaces allow us to say:  
"today it's our turn to cuddle"  
through listening, laughing, crying together.*

*We question patriarchal models,  
Systems,  
'experts.'  
From virtual spaces, because our own conditions prevent us from being able to participate in the streets,  
where our voices are not heard,  
where the structures do not welcome us.  
Having our activism in virtual spaces is a political stance,  
a disability-focused stance.*

*What does being inclusive really mean?  
The usual discourse that we are all involved and participating is not true.  
Hey, here we are!  
from our beds due to illness,  
or because of a disability,  
We can contribute, we know and have.*

*I began to lose my vision when I was one and a half.  
Today, I can call myself a blind woman.  
At the time my parents told me:  
"you are no longer going to study"  
But then there was a shift:  
"you're going to have a 100 percent scholarship to study.  
pedagogy or psychology;  
the only condition: learn braille"  
I said to myself: "In San Cristobal, I could learn Braille?"*

*My dad and I went to buy a ruler,  
an awl,  
and with my self-created alphabet,  
I taught myself braille.*

*I knew that Chiapas needed a space,  
in San Cristobal,  
a space that would provide attention to visually impaired people.  
Since 2016 with Love without borders,  
an organisation supporting women with disabilities from Indigenous communities.  
I have been walking with the support of volunteers,  
And teaching other children Braille.  
We are the only organisation that teaches Braille in San Cristobal,  
Creating shared resilience for people with disabilities.*

*Shared resilience is power  
It makes us become each others allies,  
allies from the heart.*

*At Femidiscas and Amor Sin Fronteras all that we have done*

*is without a peso [funds],  
without economic or technological resources,  
yet we have done so much.*

*We need more flexibility in funding,  
more economic resources.  
We have the creativity,  
the wisdom,  
the experience.*

*We need to be seen,  
to be heard.  
We expand the mind,  
and open the heart.*

# Estefanía Cubillos Nova

## Armenia, Colombia

***“I am deeply hurt by the many ways in which society has attempted to erase me, but I continue to go through healing processes, healing of the wounds that remain and then those wounds are like war wounds that make me stronger, tougher.”***

Estefania is a Colombian feminist activist, journalist, and Disability Justice organiser that immigrated to Panama. Through her organising and journalism, Estefanía has been a steady advocate for herself and the larger community of women and girls with disabilities. As she creates spaces and challenges ableist systems, she shows us the progressive feminist future we should all strive for. She has organised many spaces for and by people with disabilities such as a workshop that brought together young women and girls with disabilities from across Panama.

Through her poetic-political narrative, Estefania describes how her life has been about eliminating barriers, fighting oppression, and growing wings of metal. Coming from a working family from the Colombian coffee region, she shares with pride the background of her family and community, who, without many opportunities and facing continuous struggles, have been able to support and sustain each other. She expands on her journey to gain autonomy and confidence in herself and fall in love with writing. For her, this has been a tool to connect with herself, break stigmas, understand other struggles, and demand respect and justice.

*“Creo en mí” (“I believe in me”) song by Natalia Jiménez has a sentence: “after so much war I grew wings of metal.” It summarises a little bit about my story.*

*I was born in complex conditions,  
perhaps like many other girls,  
emerging in adversity is difficult.*

*First, being raised by a family of very young parents,  
with very basic education,  
in a social context where you are increasingly oppressed,  
Colombia.*

*My family is from the coffee region,  
Armenia, Quindío.  
It has few opportunities to study,  
to work.  
My grandmother and my mother were coffee pickers.*

*I was born prematurely and acquired the condition of disability.  
A condition that led to discrimination,*

*to being stigmatised by society.*

*My childhood was happiness and learning,  
playing with my jump rope,  
going on a tricycle,  
rolling in a pile of sand,  
collecting album stamps.  
I didn't realise I had a disability,  
my family treated me normally.  
In school it changed,  
the children asked me: "What's wrong with your eyes?  
So many questions and questions,  
Bullying.*

*Becoming conscious from a very early age that there was a lot of fighting to do,  
fighting to not be excluded,  
fighting to be able to be in fun spaces,  
fighting since I was a child.*

*As time went by, I eliminated barriers,  
seeking alternatives and solutions,  
getting out of this context with my mom's help,  
With the help of my family that supported me,  
who provided me with an education,  
and my grandmother who loves me very much,  
who always gives me advice.  
We are far away now, she is in Colombia,  
But she calls me and we talk,  
and when I visit her we go to the theatre,  
I tell her my love stories and how I feel.  
She gives me encouragement,  
she's a bit of a witch,  
she knows things intuitively,  
she is always connected to me.*

*We have inherited strength and struggle from generation to generation,  
also the support of teachers and professors,  
those who saw my desire to learn, to participate.  
All that struggle is summed up a bit in this song.  
"Creo en mí" ("I believe in me")*

*I am now in Panama,  
I came here eight years ago because I wanted to go to college.  
My mom had already travelled to Panama.*

*She is a stylist and came to look for better opportunities,  
and we moved here.  
I graduated with a degree in Journalism,  
the one to blame for my being a journalist is my uncle César.*

*I remember in my teenage years,  
I clearly knew what I liked to do when I began to write,  
discovering it was my thing, the written and spoken word.*

*I fell in love when I was 13 and created my own diary.  
As there were no diaries for blind girls,  
all small and inaccessible to write in Braille, I created my own.  
I began to compare my body,  
why am I so thin?  
I questioned everything,  
if I have a cane, they won't like me like that! That boy won't notice me!  
A transition for me,  
taking ownership of me,  
of my cane.*

*I knew there were tough challenges ahead,  
in life,  
in education.  
I knew I had to educate myself well,  
I found a window into philosophy.  
A professor took me one day to the University of Quindío,  
to an auditorium of 300 people.  
I was very nervous at first,  
but as I began to speak,  
I listened to myself,  
I felt calm,  
I enjoyed it.*

*After that, I began to write for the Quindío Chronicles,  
in the section "Cronichicos."  
I would write it at school.  
That was my adolescence,  
discovering what I liked and turn it into talent,  
discovering myself,  
my body,  
my sexuality,  
writing and speaking.  
I wrote a story about myself,  
of my process getting an ocular prosthesis,*

*the before and after.  
It was liberating because that was the end of the bullying,  
I saved the first article,  
And with my doctor, we published it in an optometrist's magazine.  
I continued to understand how much I liked to write.*

*I had the opportunity to go to another country.  
But there are other people who do not have enough money for college,  
or who graduated and stayed at home.  
Armenia is very beautiful,  
people have a lot of talent, and a lot of desire to do things,  
they have dreams.  
But they are not given the opportunity,  
or access.  
This is the reality,  
there is exclusion,  
there is a system that closes the doors.*

*My first act of resistance,  
in my childhood.  
I had to argue with a teacher,  
I had to fight so that he would not kick me out of the class.  
He did not like me using my screen reader in computer classes,  
tried to deny me that access,  
the opportunity.*

*Resistance is to go against all oppressions,  
against a neoliberal system,  
that seeks to reduce us,  
that tells us we have no dreams.*

*Here in Panama, with a friend  
I go to marches, and forums.  
With her, I learned that college was more than just sitting in a chair.  
and getting good grades.  
In my career,  
I needed to talk more,  
Question more.*

*From there, I entered "Agents of Change."  
of the German Frederick Ebert Foundation.  
I met a lot of people.  
A union of sex workers in Panama,  
Indigenous people,*

*all working together, defending themselves.  
I began to question a lot of things,  
become more interested in social movements,  
I became part of them,  
marching and demanding.  
I began to connect to other people's struggles.*

*I also joined a group of blind women:  
the Secretariat of Equity and Gender,  
my friend Marisa invited me.  
I think I needed a guide,  
that's Marisa for me,  
She is genuine, an honest woman who gives without any fear.  
She motivated me to apply to the Wild program in Oregon.  
I applied and I went.  
I learned with deaf women,  
I learned that I could talk to them on the phone,  
I wrote to them, they read my message.  
We broke the taboo that I was told as a child: "deaf people and blind people do not mix because  
they can't understand each other."  
I met women with disabilities from other countries,  
From many organisations, I was like wow!*

*When I returned,  
I implemented a replica of that program.  
I wrote the project,  
I secured sponsorships,  
and managed to organise a three-day event,  
to connect, share, and be with women with disabilities.  
To support each other.*

*In 2021, I organised another project,  
to talk about sexual and reproductive health with women with disabilities in rural areas.  
In an accessible and free clinic,  
deaf and/or blind women, and interpreters received their cytologies and treatments.  
With a feminist organization: Palabras poderosas,  
I also organised a workshop on menstrual management,  
Doing so without pity about deaf, blind or wheelchair-bound bodies.  
This year, we are working on a workshop on connectivity,  
bridging the digital divide for women and girls with disabilities.*

*I also worked with MADRE, a feminist funder,  
Improving grants for girls and women with disabilities.  
Making the application process more accessible,*

*so that it truly reaches those who need to be reached,  
women who do not have such a long track record,  
or maybe are not very well known,  
or who are in remote communities,  
or in precarious areas,  
or who have been invisibilised by the fact that they have a disability and other intersecting identity.  
They all have many powerful projects to implement.*

*The disability community is large,  
deaf women have less access to communication,  
it is unlikely that a deaf woman alone can have this dialogue,  
interpreters are very expensive and this is not usually covered.  
In our workshops led by them, we resolve this as they form their own support networks when they lead.  
It is necessary to change the concept of pity,  
women with disabilities can and are promoters of their knowledge.*

*Society loves us women with disabilities to be small,  
righteous.  
I question it,  
I find pleasure in myself,  
I am not afraid of what I feel.*

*My identity is diverse,  
I try to deconstruct bad and learned cultural patterns.  
I am constantly changing,  
because we don't know everything.  
I try to listen to other people,  
to learn from my experiences,  
And understand that there is more out there that I can learn about.  
I learn about other identities,  
other cultures,  
other roots,  
Form new connections,  
Become part of new processes.*

*Deciding about my body,  
the possibility of exploring the world,  
myself,  
bodily autonomy, no limits, no fears  
deciding who we I want to be with,  
how I relate,  
ownership of my infinite source of pleasure,*

*of freedom.*

*The women in my life,  
given me care and advice,  
support me when I'm tired,  
or when I do not want to continue.  
I learn from them,  
and I teach as well.*

*My mother helps me, advises me,  
although she does not understand much about activism and leadership,  
she supports me,  
women bring knowledge,  
ancestral practices,  
mutual affection.*

*I am a fighter.  
I love that I, through communication, generating listening processes,  
connection between people.  
I believe that opportunities need to be shared,  
I want people to have the access that I have had,  
I want the world to know,  
that it must be a more inclusive,  
more open,  
with more possibilities for women.  
And that in feminism, we need to bring together all of our intersecting struggles.*

*I am a passionate woman,  
committed.  
This is me.  
Following my dream.*

*A dream where women with disabilities are seen as capable leaders,  
that we have rights,  
that their wisdom and power is recognized,  
that we are resources to strengthen our organisations, communities and homes.  
And, I demand to be happy,  
I demand inclusion,  
equity,  
respect.*

# Indira Azucena Vargas

## Amazonian Kichwa, Ecuador

**“Having a disability is not the limitation... the limitation is the system that creates them.”**

Indira (Inty) Azucena Vargas is an Amazonian Kichwa disabled feminist activist advocating for youth and Indigenous women in defence of ancestral territories and knowledge, and working to further Disability Rights through her activism and community discussion spaces. During COVID-19, she worked at a community radio to spread information about COVID-19 vaccines to 11 indigenous communities. Inty has represented her community at the United Nations Gender Equality Forum, United Nations Permanent Forum on Indigenous Issues, among other international spaces, and is a member of the Youth Organization of the Amazon Region, Confederation of Indigenous Nationalities of the Ecuadorian Amazon, Confederation of Nationalities of Ecuador, Commission for Children and Youth of the Indigenous Women's Continental Liaison of the Americas.

Through her poetic-political narrative, Inty recognised her path in creating her own liberation, the power of her actions and the contributions of her work in her territory and in her life, and the pride of her community and disability – breaking away from the stigma and shame. This narrative bears witness to how stories influence the territory, and the territory influences the stories we tell ourselves, the power of ancestral knowledge, and our continuous evolution and transformation – just like nature itself.

*I come from an Indigenous nationality,  
the Amazonian Kichwa.  
I carry in my heart and in my mind,  
the struggles of our ancestors in the territory,  
the language,  
the culture itself.  
Ancestral knowledge to harvest the land,  
connections with the spirits of the water,  
the jungle.  
This is central to who I am.*

*Spiritual growth,  
connecting with ancestors,  
continuing to build the collective memory,  
weaving it with the new generations.  
Holding,  
creating bridges with other worlds,*

*the western world.*

*From a very young age,  
I read books.*

*In Galeano's words, it recognised the reality we had talked about for so long.*

*I felt it,*

*I assimilate it.*

*It was a historical milestone for Indigenous peoples in Latin America,  
to have our realities recognised.*

*Here in Ecuador,  
the arrival of the Spaniards was filled with looting,  
genocide.*

*It has marked me a lot,*

*in my political and organising formation.*

*I feel it,*

*I carry it.*

*I believe in re-claiming processes.*

*In giving critique to this context.*

*Reading about the left has nourished my training,  
my self-education,*

*and looking towards organisational leadership,  
personal and collective growth.*

*Connecting the wisdom brings something kind of utopian...*

*A new way of being,*

*a new society.*

*The 2012 national march in defence of water and life was a reminder of the injustices,  
of the way the State never sees us as a priority,*

*how our rights as Indigenous people are never protected.*

*And as Indigenous women,*

*total inequality.*

*From there, I continued my organising process.*

*And continued to question.*

*From the most personal point of view,*

*I found myself asking questions about myself,*

*about my community.*

*I was born with a physical disability.*

*My arms did not match what was deemed as the norm,*

*they kept me hidden,*

*they judged me,*

*they had all the stereotypes.*

*From my own family,*

*my mom, imposed so many barriers and judgement:*

*"you can't have a boyfriend,*

*you, no."*

*Pushing this paradigm of who I needed to be:  
A saint, pure, righteous.*

*From a very young age,  
especially in adolescence,  
I wanted to learn,  
enjoy,  
wonder.*

*I didn't have what everyone else has,  
I knew I was different,  
I broke stereotypes.  
Broke the moral structures pushed within a community,  
A forced mold.*

*Breaking away,  
dismantling this was not done alone.  
It was a collective effort,  
with my community, and a group that I am part of:  
The Organización Juvenil Común Amazónica (Common youth Amazonian Organization).  
They sustain and support me,  
women with experience in processes of struggle,  
feminists leaders,  
mestizo allies,  
Indigenous and Afro-descendants.  
A community rooted in the Amazonian territory.*

*Breaking stereotypes is not easy.  
I remember when I was sixteen years old,  
they told me:  
"you are crazy,  
you are liberal,  
you set a bad example to your cousins."  
Moralistic criticisms from older aunts.*

*I wanted to bring more of my cousins into these spaces  
Spaces of articulation, education, and organising.  
So that they would question the systems,  
the roles that they play within the territory,  
and in our communities.*

*But I was always criticised,  
I felt lonely,  
I took refuge with the organisation,  
this space held me.*

*In the community it is hard,  
And complicated to accompany the people,  
especially women.  
But I have been able to continue to reclaim our stories,  
our rights.*

*Repeating the same story: "it is an abuse that the State does not protect our rights."  
In this journey,  
I have been able to enter into movements of the anti-patriarchal women's struggle,  
feminism,  
the visibilization of gender violence  
new topics within the community  
and much more for women.  
Continuing the conversations and work.*

*One of the most profound experiences that has happened in my life is learning about other  
experiences,  
the realities beyond what I have known.  
I had the opportunity to participate in international spaces,  
learn about other struggles of Indigenous and non-Indigenous women.  
These spaces have given me tools,  
have given me knowledge,  
knowledge that I share in the assemblies,  
at community meetings,  
with my organisation,  
and in the women's circles.*

*These spaces of conversation,  
where we openly talk about what we are going through,  
share how we are not living well,  
that society is getting sicker and this is affecting us.  
Being women of the territory,  
connected to the earth is dangerous.  
The States sells our territories,  
Our entire life system,  
Us.*

*The circles within our community have allowed us to root in our power,  
to say enough is enough!  
With fire in the centre,  
with tobacco in hand,  
connecting with our wisdom,  
with the spirits.  
It allows us to talk about our experiences*

*Women's circles are a leap into the community,  
they are breaking the silence.  
Saying enough of gender violence,  
of sexual violence.  
With fire in the centre,  
with tobacco in hand.*

*We want to heal  
We want our daughters grow up without taboos,  
without stereotypes,  
we want to talk,*

*we want to heal.*

*Continuing our practices sustain and nourishes us,  
they are intimate moments that direct the struggles we have as indigenous peoples.*

*In our spaces, we understand that above all, we are human,  
we are living beings.*

*We must listen,*

*Rest,*

*Connect with fire,*

*tobacco,*

*and ask what we want as women within the communities,  
within the organisations.*

*Make our struggles heard and visible.*

*We cannot be the only ones sustaining,  
we need more women bringing these practices within their communities,  
their territories.*

*Indigenous people are healers,*

*we have medicinal teachings,*

*because we are medicinal people.*

*Indigenous people heal the physical,  
the spiritual.*

*Indigenous peoples' medicine,*

*sustains us,*

*sustain the world.*

*We cannot forget our ancestors,*

*the lessons they passed down.*

*Practices of the tobacco,*

*the guayusa at four o'clock in the morning for our conversations,  
ayahuasca, our sacred plant.*

*Let us not forget this knowledge,*

*medicine,*

*our guide in our struggles,*

*sustaining us in the spiritual realm.*

*I am grateful for my courage and willingness to follow this path.*

*I thank myself for being strong,*

*and to serve as a guide for women who have broken the silence.*

*Today, within my territory,*

*in my country,*

*the growth of capitalism,*

*illegal mining,*

*and with a State that does not care,*

*I am grateful that I know I am not alone.  
We are a collective power in this fight.  
And my daughter, my baby,  
she is the one that gives me the strength,  
now more than ever.*

*A lot of time has had to pass,  
I didn't know how to express this feeling about myself,  
of my physical difference,  
of my disability.  
It has been a great struggle to let go of the shame,  
shame of being different,  
shame that held me back.*

*Having a disability is not a constraint for women,  
we can be spokespersons,  
protect our rights,  
hold spaces for us.*

*Disability is not talked about within the community,  
or our own groups.  
We must generate these spaces,  
for Indigenous women with disabilities,  
to talk about our lives,  
our struggles,  
our ideals.*

# Mariana Veliz Matijasevi

## Buenos Aires, Argentina

***“The truth is that it is so important to be able to share our own experiences, our struggles, and to recognise our interconnection with each other. To know we are not alone – the system may want us to think that, but can’t let it crush us.”***

Mariana Veliz Matijasevic is an Argentinian Disability Rights activist and artist advancing human rights at the intersection of gender and disability. She is an illustrator and animation student that works under an artistic pseudonym that is Merion Lomari. Mariana is a militant for the rights of people with disabilities and for the rights of intersex people. She is the co-founder of Argentina Intersex, an organisation focused on the disability and intersex rights, is a member of REDI, a network for the rights of persons with disabilities, as well as part of multiple collectives, and groups working for the rights of people with disabilities and intersex people.

Through her poetic-political narrative, Mariana shares her passion of drawing and the way in which she, as she works with her pencil, reclaimed and drew her identity. This narrative highlights the power of organising with others through our shared and individual struggles. Her journey represents how we are in a continuous learning journey, and the power in embracing and drawing it in our own shape and form.

*Pencil,  
digital or the common type,  
it has accompanied me all of my life.  
Since I was very young, I liked to go unnoticed,  
I was really good at drawing then,  
I did not want to give a speech,  
but draw a comic book.*

*In the pandemic, I drew more,  
everything was done through the virtual world,  
it led me to activism,  
militancy.  
And to publish it in my networks and show it to others.*

*Drawing for me was a private thing,  
only for me.  
I never thought of sharing it.  
But it was really special that I connected with militants from other places,  
from other countries,  
it was a very cool exchange.*

*In my experience as a disabled and intersex person,  
I would share my story in comics,  
And from these stories,*

*I have met people from other countries,  
and say: wow! we are miles apart and the same things have happened to us.*

*I had a complicated childhood,  
especially after primary and secondary school.  
In my adolescence,  
this issue of the identity of persons with disabilities led me into a conflict with the context,  
with society,  
with the educational system.  
I was not keeping the pace of what was being imposed on me,  
I was making my own.*

*I come from a working class family,  
I live with my mom, dad and younger brother.  
My generation, we are the ones who have been able to study more.  
I am very close to my old lady,  
she is not very much into militancy, and activism,  
but she accompanies me,  
she asks me questions,  
and wants to learn more.  
A few months ago, she joined a talk on intersexuality.  
When we finished, she told me: "I am very happy,  
thanks for inviting me,  
I didn't know what intersex was."  
I have a lot of affection and respect for her.*

*As a teenager, I was ashamed of my disability,  
to talk about it,  
to embody it.  
I rejected that part of me.  
I also have a diverse corporeality,  
It that has nothing to do with my disability.  
People would tell me: what happened to you,  
what happened to your body?  
why do you have such scars?  
it all made me uncomfortable,  
it made me feel sad.  
And, I did not have the emotional intelligence to handle that.*

*I did not grow up with referents with corporeality like mine,  
or who had a disability,  
or who spoke proudly about it.  
In spite of that,  
I had a very cool adolescence.*

*In college,  
a light bulb moment, a teacher, an economics class,  
it led me to militancy.  
I remember being deeply touched by what he said:  
the system imposes a way of thinking on individuals,*

*what will be better for the system if individuals are separated,  
thinking they are alone?*

*That led me to look for people like me,  
who are going through similar things,  
to reach out to other colleagues with disabilities.*

*I approached REDI,  
The Network for the Rights of Persons with Disabilities,  
my school in the disability militancy/organising.  
I entered without knowing about the Convention on the Rights of Persons with Disabilities,  
I did not know the social model of disability,  
there I met other colleagues,  
with other barriers,  
different from mine,  
that led me to be able to notice them.*

*With colleagues, we formed groups such as Orgullo Disca (Disability Pride).  
In this work from the dissidences,  
we speak of transfeminism,  
of intersectionality,  
that made me feel more comfortable with myself,  
to find references of people like me;  
I feel connected to myself,  
my corporeality,  
everything I am.  
I wouldn't let anyone come in and step on me.*

*In a conversation with colleagues where they  
explained the social model of disability – saying:  
"imagine a world where there are no stairs,  
where the elevators work,  
where toilets and houses are accessible  
for a person in a wheelchair to pass.  
There would be no barriers,  
and then the concept of disability would not exist or would be different"....*

*I am an intersex woman with a disability.  
In militancy, I found pride and it strengthened me.  
First, I did not know the word intersex,  
I knew I was not a heterosexual person,  
and I was close to the LGBTIQ+ movement,  
and despite belonging to the collective,  
I didn't know that "I" was intersexual.*

*When I was an adult, I went to the doctor and learned that I was intersexual.  
When I got out of there, I thought: there are other people who were born like me.  
I went online, I searched for: intersex people,  
and found Compass Intersex,  
an organisation in Mexico with wonderful articles,  
that led me to read,  
to educate myself further:*

*Ah, so intersexuality,  
it is not this bad idea of mine that society gave me!  
To say you are a man or a woman at the same time,  
not really no.*

*This led me to look for other friends, to organize with others that are intersex.  
With some colleagues, we set up the organization Argentina Intersex.  
By learning about transfeminism,  
I recognized the cis-heteropatriarchal system,  
pushing a narrative that there is only a way to be a woman.  
But there are several,  
and one can shape womanhood as we want.  
My militancy and organising gave me many tools to build my identity,  
One that I feel comfortable with,  
one that I celebrate,  
and continue to draw.*

**Nur Matta**  
**Puebla, Mexico**

**“People that don't know me see me and want to help me to do things, then they ask me like this: ‘do you need help, do you? Or how do I help you?’ And I've found that I don't need help so much as time, time to be. Time.”**

Nur Matta is a feminist Mexican Disability Rights activist and artist that, through her art, seeks to position the perspectives of people with disabilities in a society that considers itself as “inclusive.” She is part of the National Feminist Disability Network in Mexico (Red Femidisca), has received awards for her work entitled *From Inclusion to Expansion*, and participated in group exhibitions such as *Local Dysfunction* (La Miscelanea, 2017), as well as the project review dialogue with Yoshua Okón at Museo Amparo (2018).

Through her poetic-political narrative, Nur immerses in slowness, that of her condition and of living life by giving herself more time. Time to question society, un-learn, and explore her full self. This narrative is as expansive as time itself and the interconnection of time and pleasure, especially for people whose bodies have not been given permission to take up space, to take up time, to claim, define, and feel pleasure.

*Lately I've been exploring slow paces,  
wondering what are the qualities of my condition,  
undoubtedly the slowness.*

*Dana, one of the Femidiscas members, shared with me a poem,  
A poem to explore this slow universe,  
because I have been in a hurry,  
an internal rush,  
of matching my body to the rhythm of the world.  
This poem by Luis Pescetti:  
Relief from success...*

*"I want to be the slowest person in the world  
and when everyone learns to walk, I will still crawl;  
and babble when others converse;  
to stain myself with ink, with coffee,  
and they will have to let me know;  
slow to realise it,  
to recognise it,  
to be the last to understand,  
the last to arrive,  
the last to receive an award,  
that others have birthdays and I have weeks...  
the last one to wake up,  
the one that no one expects anything from,  
I am the slowest person in the world,  
years will pass as slowly as centuries,  
far from fashions, always beyond, a relief!  
slow, slow ...  
there will be a job where someone slow is needed,  
some man will like to see me so slow, so slow,*

*with a little luck I will also like him  
without haste we will see...".*

*I am studying for a postgraduate degree in art,  
and I took the poem and read it outloud to make it my own.  
My artistic pieces talks about disability,  
and sickness.  
In art, I found a tool for understanding what I go through,  
and what happens outside of me.*

*When I started with the symptoms and these weird things,  
the medical system spoke to me in an incomprehensible language,  
with zero empathy.  
In art, I understood what was happening to me on my own terms;  
I started talking about ramps,  
denouncing the lack of accessibility...  
I realised that I didn't care so much about the ramps,  
as the gaze,  
the gaze of others,  
the looks of curiosity or pity.  
I also had that look I gave myself,  
was my own judgement of my condition.*

*In September 2021, I moved to Mexico City,  
a month with diarrhea!  
"I was literally scared shitless."  
And then, I find myself in an incredible place,  
it no longer makes sense to talk about disability.  
In the ways I was doing it;  
In the postgraduate art course we were welcomed...  
a colleague turns to me and says:  
"let's go out for a drink".  
My prejudices towards myself rinsed away,  
she did not see me as sick,  
or only as a person with a disability.  
She saw me as an equal to her,  
here my body is something else.*

*I had a project,  
One focused on the representation of women with disabilities in telenovelas (soap operas),  
the 'damned cripple.'  
I watched one hundred and ninety episodes of María la del Barrio.  
I started to make a selection,  
then I shared them with my colleagues with motor disabilities,  
I wanted to see what it felt like and what it was like to see that performance.  
It was very heavy, hard, overwhelming...  
because within this research,  
I am in the middle;  
There but looking for other things,  
ironically as an escape from myself.*

*I started to want to explore from another place,  
not so much from other's point of view, but within myself,  
Asking: what happens to me?  
What happens to me with this?  
I wrote an essay "From Inclusion to Expansion".  
it was very hard but very rich.*

*Inclusion?  
I was skipping the inclusive, 'good-natured' wave.  
It bothered me so much.  
Until I heard a talk in Puebla with Pato Bustamante,  
there a lady in the audience shared some words,  
she said: "there is a lack of education, we need to educate ourselves".  
and Pato responded:  
"Why don't we uneducate ourselves?  
why don't we re-educate ourselves from everything we think about disability?  
why don't we talk about expansion".  
It made a lot more sense to me  
because when we say inclusion, what do we mean?  
In what terms will it be inclusive and who will be included?  
And who will be left out?*

*Unlearning is not so easy,  
It has been an exercise of confronting myself,  
my environment,  
ask myself a lot of questions,  
what have I learned?  
Talking with Beatriz Miranda, an eminence in disability studies,  
gave me the confidence to be sincere.  
I would say to myself:  
"Nur, you have to talk about this.  
because they always talk about disabilities and sickness without those that experience,  
without us."  
I have also become aware of other capabilities that I have,  
Leonor Silvestri has a sentence  
"...so much expansion of limits when in appearance it shortens and narrows me".*

*It also made me think about my mom,  
I had a bad relationship with her from all of this.  
She has had to change my diaper when I was twenty-two years old.  
We had to become allies,  
and our relationship has improved a lot,  
I respect her a lot,  
She has gone through it all with me,  
accompanying me through each moment.  
Yesterday I was running,  
then I was diagnosed with lupus on a Monday,  
by Tuesday, my mom taking me to college,  
dragging me to continue.*

*It was helpful,*

art, the University.  
Helping me to cope with all this.  
Now I want to go immerse in my body,  
create a slow universe,  
invite people into this universe,  
to this temporality that inhabits me.  
Art gives me the possibility to explore my condition in these ways.

With the Femidiscas, I have been able to share from other perspectives,  
recognise our interdependence and to be each other accomplices.  
In this community, I have been able to enunciate myself politically,  
reclaim who we are,  
women with disabilities.  
There I put my contributions,  
Dana, Ana, and myself, who have motor disabilities,  
we held a forum to discuss the telenovelas project,  
curiously, people who do not have a disability were connected,  
and then, we received messages saying:  
"I realised that my view of disability is paternalistic,  
or ableist" ...  
Reading how new outlooks opened up,  
new points of view of what it is like to be a woman with a disability,  
this is my grain of contribution ...  
With them there is no duty placed by the collective,  
our ties strengthen us,  
our trusts,  
this makes me contribute the best of me.

Now, I find that my resistance is in the erotic.  
I would like to go that way,  
there are women who are denied femininity,  
especially women with disabilities.

My resistance is going towards allowing myself to be feminine,  
to be beautiful,  
to be sensual,  
to feel pleasure.

Giving myself a chance to feel beautiful and sensual,  
letting my body enjoy this pleasure is a way of resisting.  
People are going to judge, and there will be internalised shame.  
But I decided to give myself permission,  
to take up space and create space for others,  
exploring and living in our bodies,  
reclaiming our pleasure.

If I feel like I want to wear lingerie, even though I'm wearing a diaper underneath and still feel  
shame to say it,  
I to say it out loud and honour the courage it takes to do it,  
to allow myself to find and explore myself.

*With Femidiscas, other women with disabilities, and with women who do not have a disability, those who have been told that you are a fool, not taken seriously, ripped from their autonomy, we can give ourselves permission to be ridiculous, to un-educate ourselves, to re-learn and explore and celebrate our full self,  
To be beautiful,  
To be sensual,  
To claim, define, and feel pleasure.*

**Monica Yeanie Ghaliwa**  
**Freetown, Sierra Leone**

***“I knew we needed to raise attention and an alarm about the violence girls and women with disabilities face. I said we need to fight. We need people to know this is happening to us.”***

Monica is a Sierra Leonean Disability Rights activist, journalist, and non-profit founder. In her personal and professional life, she is determined to challenge the norms and narratives facing people with disabilities, especially girls and women, in Sierra Leone. She innately understands the potential and power of using the media in Sierra Leone to draw attention to pressing issues facing people with disabilities. Orating her story here, she believes in the power of both individual and collective action to create change.

*I am a young woman. I am a daughter and a sister.  
I am a journalist. I am a teller of stories.  
I am a Disability Rights activist and advocate.*

*Our identities change as we grow and experience life. At 18, I lost my eyesight through glaucoma. This is a condition where the nerve gets damaged. So for me, I didn't just wake up one morning unable to see – gradually, everything dimmed. My trips to doctors for treatment and to my church to pray didn't change this.*

*After my diagnosis, I decided to study more, to change my situation. I went on to secure a diploma in Mass Communication and Journalism and to become an intern and then staff member at the Sierra Leone Broadcasting Corporation (S.L.B.C. – the national radio and TV broadcaster in Sierra Leone) – in this space, I found my passion in advocating for people with disabilities. I asked for and then hosted a radio programme called disability hour – one hour every week, where we would bring in policy makers and discuss the issues people with disabilities face and the gaps that exist.*

*Then came Big Brother in 2019 – a reality TV show. I applied even though people around me discouraged me. I knew that if I could be on a show like this, I could change the narrative in Sierra Leone about people with disabilities. I applied and got on the show! People were so confused and even said I couldn't be blind because here I was, doing everything for myself. I was able to use this platform to show that even though someone might have a disability, they still have abilities.*

*I didn't win Big Brother but I received a prize as runner up. With this money, I set up an organisation called Inspiration for Human Development to support people with disabilities. When COVID came in 2020 – the information being shared about prevention really worried me. As a person who is blind, I am at risk – how do I avoid physical contact with people when I can't move or walk alone? If I am blind, how do I get the information if it isn't in Braille? I knew that we needed to get the messages out to other people with disabilities. With support from U.N.F.P.A., I distributed kits with face masks and sanitiser in three communities in Freetown. I then went on*

*to work as a volunteer Social Mobilisation Officer with U.N.D.P., the Ministry of Social Welfare and One Family People, a local N.G.O.*

*Today, I am part of a programme with Plan called She Leads. I am the only young woman with a disability in the group. I also still work with S.L.B.C. head office in Freetown and continue to use this space to create awareness about disability – I host a youth programme every Sunday called Youth Magazine.*

*Because of my platform, people come to me with stories.*

*Last year, one story led me to join with other women and girls with disabilities in protest. This story is about a 24 year old woman in Freetown, she had a speech and hearing impairment – her name was Agnes. She was also a mother and a daughter. On her way back from a postnatal appointment, her mother asked an okada driver to take her home. Her mother paid the driver and told him that Agnes couldn't speak but that Agnes knows where she lives and told him the address. Her mother took the baby and took a separate okada home. When she got back home, Agnes wasn't there. The family went to the police. Agnes was missing for five full days. When they found her in a field, she was hospitalised. She was able to tell her family that there had been three men. Agnes later died in hospital.*

*There weren't any suspects but I knew we needed to raise attention and an alarm about the violence girls and women with disabilities face. I said we need to fight. We need people to know this is happening to us. I went to capture the story, and I interviewed her mother. Others went to other media outlets to raise awareness of this story and the issue of the violence we face. Across different TV stations, we talked about it and we arranged a protest among twenty of us women with disabilities. We wore black. We met with the Chief Police Inspector, the Attorney General and the Minister of Social Welfare. We demanded our safety. We demanded that police officers be trained in sign language so they can communicate with survivors.*

*This is a battle that we must keep fighting.*

*People with disabilities are out in the street, every day the cost of living is rising and more people are in the street. We need to take action.*

*I like to break the bias, there is nothing we cannot do. Yes, I lost my sight but I knew I could redefine my life to support others.*

*I want inclusion in every aspect of life.*

## **ACKNOWLEDGMENTS**

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stories of resistance, and the power of the Disability Rights movements in pushing forward the feminist and human rights agenda, as there is no feminism without Disability Justice.

This publication has been woven together by Catherine Nyambura, Emma Mulhern, Eve Alcalá González, Jody Myrum, and Laura Vergara, edited by Rochelle Jones, illustrated by Abi Stevens, and designed by Laura Vergara.

### **Storytellers:**

- Anisie Byukusenge, Rwanda
- Aminata, Sierra Leone
- Crystal Asige, Kenya
- Elizabeth Patricia Pérez, Mexico
- Estefanía Cubillos Nova, Colombia
- Indira (Inty) Azucena Vargas, Amazonian Kichwa, Ecuador
- Mariana Veliz Matijasevi, Argentina
- Monica Yeanie Ghaliwa, Sierra Leone
- Nur Matta, Mexico

### **Voices/Quotes**

We intentionally limit edits to reflections shared by each storyteller. Even with translation, we try to remain true to their words to ensure we are honouring their wisdom and experience. Some of the contributions presented in this publication have been translated from Spanish and Krio.

### **Further information**

Follow our social media channels for more insights and learning from our work. If you have a specific question about this work or report, please email us at [info@wearepurposeful.org](mailto:info@wearepurposeful.org)