

To provide you with more insight into the development of this exhibition, we're sharing a conversation between the artist and a correspondent. The correspondent was not familiar with the artist's work and, like you, has discovered through this dialogue the often invisible choices made during the creation of this project, as well as in the artist's general working process.

**Jenni-Juulia
Wallinheimo-
Heimonen**
in conversation with
**Christopher
Samuel**
as part of the
exhibition
**WHEN I GROW UP,
I WILL BECOME A
COAT RACK**

1 Parallax Robot
Meccanoid 2.0. XL, textile sculpture.
Fabrics, beads, crystals, sound.

2 Could You watch my Mom for a moment?
Installation. Motorized wheelchair,
textiles, beads, embroidery.

3 Reflector of Living Will
Short film about care robot protecting
people from human caretakers.
Cast: Marja Pelkonen and Milla-
Emilia Mutka.

4 How Great is Your Darkness?
Comedy film about hate speech
towards people with disabilities in
health care. Produced by Kenno
Filmi. Music: Kemal Gorey.

5 Flying Walker
Performance object. Walker,
crutches, reflectors.

**6 Sound machine of prosthetics
of Merthyr Tydfil**
Automata mechanical sculpture.
Wood, chair, shoemaker's lasts.

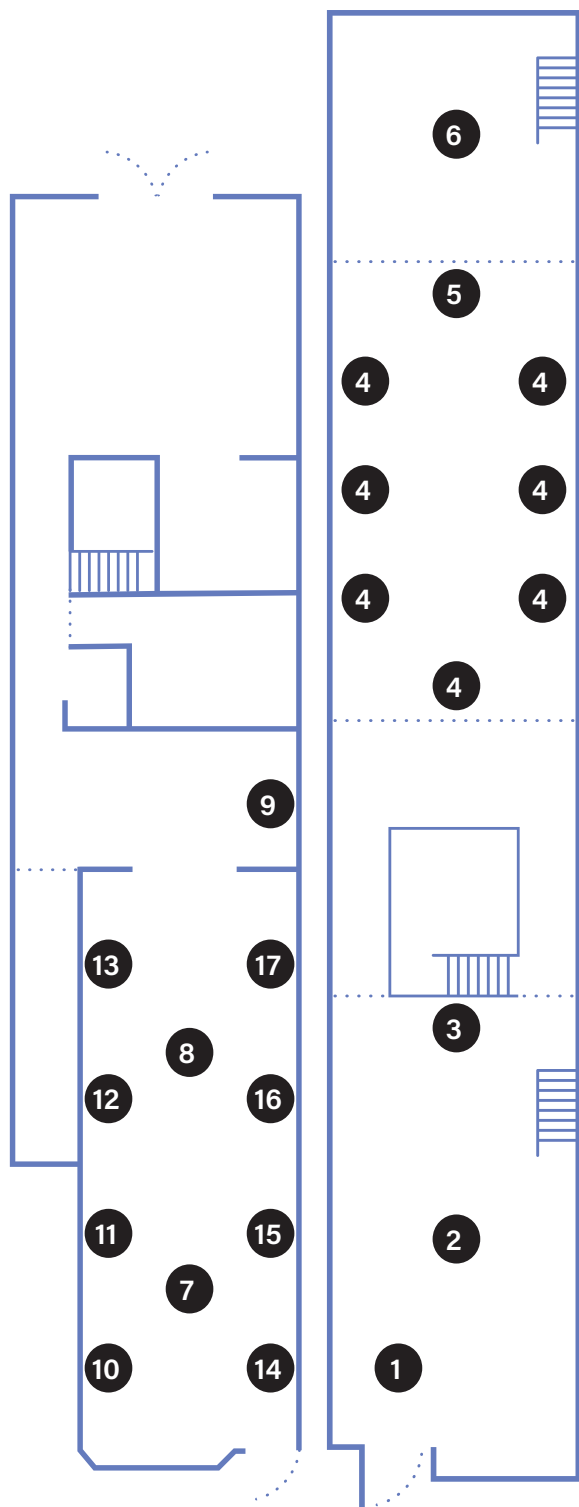
7 Blind Car
Recycled textiles, polycarbonate,
Arduino, white cane, beading.

8 Decoding Sole-Mates
Community art documentary testing
Hume by Mentech SentiSocks which
measure stress. Cast: Raisa & Reko
Valavaara.

9 Locking the door
Textile sculpture, motor.

Pauper Statues series
Bass wood, carving, textile and beading.

- 10 Mouse trap**
- 11 Riding into the Parlor**
- 12 Christmas in Katthult**
- 13 Fermented cherries**
- 14 You and me Adolf, you and me.**
- 15 Another mischief**
- 16 Mayor's Wife and blueberry soup**
- 17 Snow storm**



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For more information about this and other projects,
check our website or scan the QR-code:

1646.nl



Jenni-Juulia Wallinheimo-Heimonen

Jenni-Juulia Wallinheimo-Heimonen (b. 1974) is a multidisciplinary artist and disability activist who works with textile art, installation, film and performance. In 2024 she was one of three artists selected to the Pavilion of Finland at the 60th International Art Exhibition – La Biennale di Venezia.

In 2019 Wallinheimo-Heimonen received the Finnish State Prize for Multidisciplinary Art and in 2018 her short film about care robotics (*Reflector of Living Will which comes to 1646*) won the Best Screenplay at Pisa Robotic Film Festival. Wallinheimo-Heimonen's work spans from sculpture and film to performance and activism within disability politics and policy. She has facilitated workshops in Finland, Bosnia-Herzegovina, Estonia and China and participated in exhibitions in Finland and abroad.

In 2022, Wallinheimo-Heimonen worked in the Harbourfront Centre Toronto artist residency as part of the Nordic Bridges programme and participated in the 8th Biennial of Contemporary Art Fundación ONCE in Madrid. She holds a BA from Aalto University, School of Arts, Design and Architecture in Helsinki. She has osteogenesis imperfecta as a piquant characteristic.

27/12/2024

Hi Jenni-Juulia,

Sorry for the delay in getting back to you.

It seems like I've been apologizing to everyone this past year. Apologizing for being disabled and not having the energy levels to do the things I would like to do. But as I'm writing this, it's making me laugh because I constantly talk about the importance of crimp time. Yet, I still feel a deep sense of shame, embarrassment, and like I'm letting people down. I know that's a load of nonsense to a degree, but it lingers.

Anyway... how are you?? Merry Christmas! How's the Finnish snow? I wish I was there. We've had no snow, which is very disappointing.

Thinking about the exhibition, I think the opening line after the title of the work is a big question—an important question for me and other disabled people. As someone who's experienced having the ability to make decisions taken away, I know how vulnerable that feels. Particularly with carers or being cared for, the people who were supposedly looking after me put me at great risk in the past and took my autonomy away.

For instance, I was told when I needed to go to bed, when I needed to wake up, and when I needed to eat. A big issue is also where my funding for care comes from, how it needs to be spent, and the stipulations imposed by the government and local authorities. They often suggest that certain care companies are more legitimate, more regulated, and therefore better for the disabled person. But that's not the case.

In fact, I think it's the complete opposite. Many of these companies aim to receive money without providing proper care,

which is evident in their bad practices—staff not being trained properly, underpaid staff, overworked staff... the list goes on!

I have many questions 🤔 and I'm curious to know a bit more about your thoughts on these topics:

What are some potential benefits of including disabled people in decision-making and technological innovation? What are the consequences of excluding disabled people from medical and social infrastructures?

How does the exhibition "When I Grow Up, I Will Become a Coat Rack" encourage critical thinking about inclusion and awareness?

In what ways does your work highlight the unnecessary dependencies between the disabled community and existing infrastructures?

How might technology change if it were developed from a place of joy and pleasure rather than profit and efficiency?

What does Jenni suggest about the concept of "normal" and its impact on disabled people?

How does the support from the Finnish Cultural Institute for the Benelux and the Alfred Kordelin Foundation contribute to the exhibition's goals?

What role does humour play in your art approach when discussing disability?

How can society better prioritise quality of life over ableism in technological advancements?

It was nice exhibiting with you at MIMA, and I'm thinking about when we had to give a talk to the visitors who came to see the show. I liked what you did, it was a performance which I thought was really interesting and engaging. Will you be doing another performance for this show when it opens?

Speak soon,

Chris

31/12/2024

Dear Christopher,

Crip time greetings from the embrace of a radiator. Behind the window, the landscape is darkened by climate change. Sadly, there's no snow to send your way either. Shall we rent an ice cream machine instead? Happy New Year!

Thank You for sharing your experiences and for your inspiring questions, such as the benefits of including disabled people in decision-making and technological innovation.

I hope we'd be spared from inventions that satisfy imaginary needs. In my film about a care robot, the main character isn't excited about a patronizing fridge that reminds her when she is running out of milk – because she buys it when she has the money, not when the fridge wants her to. Without us, innovations like the Internet of Things may miss solidarity-driven solutions, like appliances that scan the neighborhood for surplus food nearing expiry and connect it with those in need.

I love how the UN office of Outer Space notes that if the International Space Station, in the Province of ALL mankind, were blind-friendly, it would be safer for all during power outages. Finland should reflect on this wisdom now, as the anchors rake the bottom of the Baltic Sea for telecommunication and electricity cables.

Imposed eating and sleeping schedules are a perfect/hellish example of what happens when we're excluded from medical and social infrastructures. They reflect how superpowers justify intervening in other nations' affairs. Isn't it ironic that we're underrepresented in healthcare professions, despite being excellent to promote structural changes

and a good life with impairments? I have joked with doctors that if they joined us as allies in shaping disability policy, much of their work would shift to architects, designers and policymakers. In Finland you still need a doctor's appointment just to get a ramp for your sauna door - unnecessary dependencies!

How might technology change if developed with joy and pleasure in mind – this is one of my passion topics!

In 1646, the idea of a blind driver installation ties to young visually impaired people critiquing self-driving car designs for ignoring the empowering joy of driving. With today's technology, safe, tactile feedback via steering wheels, gloves, or other interfaces could let them experience the thrill of driving. (in a survey years ago, young men were more likely to get assistive devices for leisure cruising with friends, while women had to justify theirs with rehabilitation or even weight loss. Hopefully this won't repeat when blind people apply for robotic car subsidies!)

The new video in 1646 follows a couple with developmental disabilities, monitored using soft technology from the Dutch company Mentech. The SentiSocks track stress levels, providing caregivers with early warnings and encouraging stress-reducing interventions, such as music or touch. The socks are originally designed to improve the quality of life for people with speech impairments or memory loss.

You mentioned humor, which I weave extensively into my work. I'd love to discuss it further in the next letter – and as a counterpoint, reflect on what drew me to your piece at MIMA. I admire how you narrate moments where disability offers no hiding place from punishment or peculiar family dynamics.

Today marks my final day working with the support of the Alfred Kordelin Foundation. I'm deeply grateful for their help, along with 1646 and the Finnish Cultural Institute for the Benelux. Their support made it possible to create two new works for this exhibition, commissioning music from Kemal Gorey for *How Great is Your Darkness?* film (from audio description) and receive mentorship that fosters lifelong learning.

Wishing You curiosity and inspiration for 2025!

Warm regards,

Jenni-Juulia

02/01/2025

Hi Jenni-Juulia,

Thanks for your amazing response! "Crip time greetings from the embrace of a radiator" – that's funny but a brilliant way to open! It sounds romantic in my mind, but the reality of the cold and snow isn't for the most vulnerable! I'm not sure we need an ice machine! Ha.

I appreciate you saying nice things about my questions and experiences. Your thoughts on including disabled people in decision-making and tech innovation are so spot-on. I agree about avoiding inventions that nobody actually needs. Your example of the patronizing fridge is perfect – it really highlights how important it is to design things with real people and their real needs in mind, not just what someone thinks they need. And the idea of appliances sharing leftover food with people who need it? That's such a powerful example of tech that's actually about helping people, and we definitely need more of that kind of thinking.

This is something I've always pushed back on as far back as I can remember. I remember being furious about this. For example, horribly designed wheelchairs (that look like things of torture or were created in the Stone Age). Also, let's not forget how overpriced and extortionate these aids are. I find it really sad that a wheelchair costs as much as a car, and the ones people really need are out of reach for obvious reasons.

Your point about the International Space Station being designed to be blind-friendly so everyone's safer during power outages is just brilliant. It perfectly shows how designing for inclusivity actually makes things better for everyone, not just the people it was originally intended for. That is an interesting point, but I'm somewhat skeptical about this. I think history has shown us that if you don't have value, then

you're not considered. So, I don't think disabled people would be invited to space stations anyway. But able-bodied people, animals, plants, etc., yes.

Your comments about Finland and the Baltic Sea cables are a significant reminder of what can happen when accessibility isn't a priority. But I think we know what's at play here: money and politics!

Eating and sleeping schedules were/are and will continue to be "perfect/hellish." It's a stark reminder of what happens when people are left out of the planning for medical and social support. The irony is that disabled people are underrepresented in healthcare, even though we have so much to offer in terms of making things better. I don't want to sound negative, but the reality is that until something directly affects someone (an able-bodied person), there's no real need for those in positions of power to change how things work because it doesn't affect them. This is why open dialogues, representation, and people being brave enough to make change are important.

Your joke about doctors teaming up with us as allies to help shape disability policy that will, in turn, help their work and shift it to architects, designers, and policymakers is genius and really gets to the heart of the problem. Needing a doctor's appointment just to get a ramp for a sauna in Finland? Seriously?! That's a perfect example of how unnecessarily complicated things can be. It's me being skeptical again, but I think how doctors are trained is a key area to start from because if they are being taught from a purely medical model and with their medical gaze in mind, there isn't room for them to make space for us to shift cultural ideas around disability.

I'm just as passionate as you are about how different technology could be if it was designed with joy and pleasure in mind rather than just profit and efficiency. As I touched on earlier, I think this would have a profound effect on society and on how disability is viewed on both sides. It's a win-win!

The story of the blind driver installation in 1646 made me smile. The possibilities we have now with tactile feedback sound out there, but it is possible. I think it's important to remember the simple joy of things like driving and to make sure that assistive tech actually adds to that joy rather than taking it away. I remember starting the process of applying to drive and the assessments I had to go through before I was allowed to drive. In my mind, I prepared myself to be disappointed because I thought they wouldn't have the right assistive technology that would enable me to drive.

But also, my needs were very different from those of other people with disabilities growing up. There's always been this one-size-fits-all approach when it comes to different aids that could assist me, whether that be grab rails, poorly designed wheelchairs, badly designed clothes, badly designed phones, inaccessible buildings, or inaccessible cars.

Anyway, long story short, my car was designed and adapted to fit my specific needs. The effect it had on me and my life was profound and brought me an immense amount of joy. It brought me the thrill of driving, the thrill of freedom and independence, and the feeling of being part of humanity and society.

Your point about the survey on assistive devices and how men and women had to justify them differently is a really important reminder of how biases can sneak into tech. I really hope, like you, that we don't see those same biases popping up. Well, I think it's happening, so I retract that point, haha. For example, you can see this in AI, and those who are programming/coding naturally come with their own biases.

The SentiSocks project sounds absolutely fascinating! It's such a great example of how tech can be used to genuinely improve people's lives.

I'm really looking forward to chatting more about humor with you next time, and I'd love to hear more about what you thought of my piece at MIMA. I really appreciate you saying such nice things about how I write about those moments when disability leaves you nowhere to hide.

Huge congrats on finishing your work with the support of the Alfred Kordelin Foundation, 1646, and the Finnish Cultural Institute for the Benelux! It sounds like that support has been absolutely invaluable for creating new work and learning so much.

Wishing you an amazing and inspiring 2025 too!

Warmly,

Chris

04/01/2024

Hi Chris!

Snow fell from the sky on New Year's night. I'd love to send you that magical feeling – as a sticker for your window 😊. As you said, the reality—icy roads and unplowed sidewalks keeps people locked in their homes. This segues to a flying walker sculpture.

I joke about flying aids and space travel, which must be literally the most exclusive way to move around. In the Guide Bird project for visually impaired people, I imagined Mary Poppins-style flights using birds' ability to navigate by reading the magnetic fields (with the bonus of eggs for lean days). The flying walker, meanwhile, is a solution to slippery surfaces—falling is my greatest fear due to the brittle bones - after Putin. (In sparsely populated Finland, flying might work, but between the skyscrapers...)

You mentioned the cost of assistive devices. I wish I knew how we could lobby decision-makers, ensure free access worldwide, provide resources for innovations, address energy needs, sustainability – and empowering design. We should brainstorm this together! It's not fair if only the wealthy or influencers with GoFundMe campaigns afford them. I'm so glad your car process went well—whether it's a car or a spaceship, what we're really talking about is freedom!

In Finland, assistive devices are available through public healthcare, but the cuts have made the process less personalized. If a welfare region has tendered a supplier, people are limited to their options instead of getting what suits them best. Even prosthetics are subject to cost-cutting—people are sometimes denied a second robotic hand, even if their job requires two. As if unemployment with one hand is somehow cheaper? I can only imagine

if someone needs four limbs? (there's always that strange feeling that I should only be grateful for living in a country that used to be a welfare society and for what I receive and not criticize - of course I am. But where can change come from if we don't dream about it aloud and together?).

I'll bring one of "parasitic prosthesis" to 1646, a joke inspired by a workshop in Bosnia where veterans told me the most important features of prosthetics: To make money and attract partners. I got sick with prosthesis jealousy and designed one that could sell ad space—no limb loss required. Why stick to the stereotype of two legs if four could improve my balance better? If there were enough arms, a flying walker wouldn't be needed, as the arms could work as wing bones under a cloak.

This letter is getting a bit surreal and is full of segues— I'm thinking of your piece "The Archive of An Unseen" (2023). It's not here now for recall, but I'll write from memory how it struck me at MIMA. I hope it's not impolite to say it felt like watching an intimate multilayered film, with a track of hidden "comedy" for insiders only. A life story where the setup is a disabled person's growth narrative (perhaps engaging or teasing a non-disabled audience's curiosity?), but where the punchlines were truths that many struggle to accept or fundamentally believe. Like: the clumsiness of the healthcare and its dehumanizing attitudes and language (even when the intentions might be good or framed as kindness); the inaccessibility of services without a fight (that people without disabilities assume they will automatically receive if needed); intersectional discrimination; or how non-disability-related factors in our environments and family history shape us more than what "others" see in us.

I don't accept corporal punishment, but your anecdote about feeling treated the same as other kids when you received the same punishment - highlights (like joke or sarcasm) how deeply inequality is embedded in structures and everyday interactions. The way you told your story felt truly Unseen. Thank you for sharing and for your sophisticated humor!

A little confession: the care robot at 1646 will be telling disability jokes, which may be a catastrophe. For some even the non-ableist humor about disability is off-limits, but here's one of my favorites, what do you think?

Passengers were waiting on a plane, which stood on the runway leading straight into the sea. Finally the captain arrived with his guide dog, followed by the pilot using a white cane. The plane started moving and the sea approached. In the final moments, the passengers began screaming, and the plane took off. The captain turned to the pilot and said: "One day these woke folks are going to scream too late."

Happy New Year!

Jenni-Juulia

07/01/2024

Hi Jenni-Juulia,

Happy New Year!

Each time I read your responses, you always make me laugh right from the opening. Ironically, guess what? It snowed here a few days ago! I was hoping to be snowed in, but it didn't settle. Still, it was wonderful to wake up to snowflakes and see a good amount of snow outside my door.

Flying walkers and space travel. Again, that's hilarious. Count me in! I can totally picture you flying Mary Poppins style, leaving a trail of snowflakes and laughs as you pass. The guide bird project is brilliant, pure genius if I don't say so myself. As I mentioned before, in regards to the cost of assistive devices, don't even get me started on that subject again.

With my limited understanding of how funding works in Finland, is there a collective will to push against the system and demand changes in how disabled people are treated? It sounds like a stalemate—to be in a position where being grateful for what you have and not criticise— means you can't ask (or hope) for better.

It's frustrating that essential tools are out of reach for so many. I think we definitely need to shake things up and lobby against the decision makers who are creating these policies. Maybe we can start a protest? A Protest on Wheels campaign, perhaps?!

I know this is a big question, but what has your experience been like navigating the intersection of healthcare, assistance provision, and wanting to work in Finland? I'm asking because it's a total minefield in the UK! Navigating between the support you need, and the role you want to play in society. Disabled people have to fend for themselves to get what they need.

On a different note, I want to thank you for your incredibly kind and thoughtful reflections on *The Archive of an Unseen*. Your beautifully written insights captured its essence so well, thank you for that.

I think we must continue sharing these stories and truths to foster understanding and empathy. It's essential for the world to see the reality of different people's experiences, particularly through the lens of disability. There's so much to learn from that.

As for the care robot telling disability jokes, again, I am constantly laughing reading your responses. Why not add a bit of humor to the mix? It brings people in and reminds them we're all human. I'm curious, though: what responses have you received when using humor in your work? Both the good and the bad? What's the best or worst response you've had? (I'm always interested in both!)

Your idea of selling ad space on prosthetics is genius. I've never considered selling ad space on my chair, but maybe I should! If you could have just one extra limb—be it an arm, a leg, or even a wing—which would you choose?

This might get me canceled (but here goes anyway): Why did the wheelchair cross the road? Because it was *rolling* with laughter.

But anyway, I think it's important to keep dreaming and working toward a more inclusive future. I'm all in for brainstorming and finding innovative solutions together because, after all, we're talking about freedom and equality for all of us.

I wish you a creative, prosperous and happy, progressive year. And cheers to the future.

New beginnings and shared dreams.

Best wishes,
Chris

09/01/2025

Hi Chris!

Greetings from an old grump who's under pressure to be funny. I'm glad you got a glimpse of snow! My grandmother always said, "Don't eat snow until all the birds have flown south."

Weather report: When-Finland-wants-to-kill-you season (delightful combo of snow turned to black ice topped with rain).

I'm so ready for the big, international protest campaign with you—how about we start by rolling with laughter over the worst laws and regulations? What should we do next?

My experiences with accessing assistance services are mixed. In living with OI, the needs vary depending on fractures. Over time, I've learned to fill out the right keywords but working on grants hasn't always been recognized as "real work," but rather as a "nice hobby for someone like you." I get assistance with household chores, but in the studio, I work alone on the floor, slowly, stitch by stitch. In packing crates or carrying heavy materials, my stepfather Jaakko Mäkikylä has helped for the past 20 years—along with my husband and friends.

On the bright side, I've had luck with hearing aids and their maintenance. But only because I've been outsourced to private providers as my work involves public speaking—which is unfair. Everyone should get help quickly when their device mutes (always at the worst possible moment, like 15 hours before a work trip). Someone should write a book about the soul of assistive aids—mine are afraid of flying. When do your aids betray you?

How have you managed to balance being an artist and accessing services?

Finland just passed a disability services reform aimed at including people who've previously fallen through the cracks (e.g., people with concentration, behavioral, or neurological disabilities). Sounds great, right? Except the government is already watering it down. Our finance minister's motto is: "Empathy has no place in politics." They tried to include a mysterious phrase, "things that belong to an ordinary life," in the law, which would allow social workers to interpret it however they please (could being an artist ever pass the "ordinary life" test?). The new law is also a step backward ideologically, focusing more on care than on individual needs.

You can get transportation services for work or study trips in Finland, but only to one destination once a day. That doesn't work in today's job market or for freelancers. Employers could get support to make workplaces more accessible, but nobody advocates for it. Our employment rate is shockingly low, leaving many to live their entire lives on minimum social benefits. Recently, the government also removed the allowance to earn €300 without losing benefits. If the UK is a minefield in this matter, then here we are in the middle of a movie scene of Bambi slipping on a frozen lake.

Maybe we should start selling ad space for our livelihoods since we're already stared at. It's impossible to play a copywriter in English (sorry for the clumsy idea), but how about an ice cream ad on the back of your chair: "Do you prefer Smoothie or Rocky Road flavor?"

And about your extra limb question—how to say this decently...

... as a short, middle-aged woman walking with a crutch who's constantly being mansplained to (not by you!), I obviously need... Just kidding!

I need a kangaroo pouch to carry all the stuff in my purse and backpack without crushing my legs, and warm enough to keep hands cozy on freezing days—at least the one not holding a crutch. What extra limb would you pick?

My humor is a deep question: does it come from real joy, or is it like a court jester trying to make the king laugh to avoid losing their head? The best feedback I've gotten was that I make non-disabled people jealous they aren't disabled yet. The worst? The slur: "It's lovely how you cheer up disabled people" or "We're all a little disabled, aren't we?" Last one feels like cultural appropriation, don't you think?

Looking forward to hearing from you. In the meantime, I'll be trying to avoid the Bambi moments!

All the best,

Jenni-Juulia

11/01/2025

Greetings, greetings Jenni-Juulia, How are we doing?

Hello from a really cold England. It's currently -4, and everything is frozen over. There's a lot of black ice everywhere here, too, which will be interesting. I quite like the idea. Well, I've always liked the idea of skating in my wheelchair, sliding around even though I slid and slid off the curb once. Luckily, I was with someone who stopped my chair from toppling over. I think your grandmother raised an interesting point. It made me think about my eating consumption of snow. I am still alive, so I guess it is not that bad. Like I said, I am definitely all in for an international protest campaign! Yes, we could start by looking at or picking out the worst regulations, and we can create a tier list of top-tier ridiculous ones through to not so bad. What do you think?

I'm always intrigued and interested in how other disabled artists work and curious about how other people engage with accessing services. Hearing how you navigate that has brought a smile to my face. I know how frustrating and hard it is. I think disabled people are like weeds. I'm quoting another disabled activist, artist, campaigner, and troublemaker who said this to me. They're hard to kill. This is always a great reminder of how resilient we are and how imaginative we are trying to figure out how to navigate systems to make them work for us like what you're doing.

It's great to hear that you've got a great support team around you. I think that's paramount for us as humans and communal human beings. But also it's quite sad because I'm equally reminded of other disabled people on the margins who don't have the resources or the energy to fight against and push against the system to exist and be part of society or to be visible.

This is great fuel for me to keep on responding to things that piss me off. It's funny what they think artists do and the lack of importance and value. But also outdated/poor expectations they have and place upon disabled people. For instance, like you said, it's a "nice hobby for someone like you." We know what that means and where that comes from! I've had multiple comments in the past saying, "It's great that you're trying" ... "It keeps you busy and gives you something to do, well done."

There's a system in place (UK) in terms of support for access to work, and there isn't a box that you can tick that's recognized in terms of artists as a vocation. So that's always something I look forward to when I'm being reassessed to justify why I need help and support.

You're so funny! About the reliability of your hearing aids and it betraying you. But also, I think I mentioned before that people do not have access to the right assistive technology too. How sad is that because you work, you only now have access to better private providers.

What is funny, is that as soon as you are considered doing something like contributing to society in some way, then you're given slightly more options. But in regards to England, you have to pay for anything extra, which is completely unfair.

My assistive technology has betrayed me a few times. It tends to be my electric wheelchair, and it always happens on the train when I'm traveling. I switch my chair off when I get on to conserve battery life. As the train pulls me into my station, I've switched the chair on, and its computer is frozen, which means I can't move at all. And the way to navigate that is, there's a small switch underneath the chair at the back, hidden away. Luckily enough, there have been a few people that I've had to ask, strangers, to go behind my chair and

underneath it and search for this button to be switched off and then switch back on to reset the computer in the chair. There are some really good people in the world!

"How have you managed to balance being an artist and accessing services?"

How have I managed to balance being an artist and accessing services?....

It's been a lot of work, and I'm constantly juggling what I need because the landscape is constantly changing. So over the few years, I've managed to find a group of people or a team of people who do different things that support me in different ways. Someone who helps with writing applications, someone who helps with supporting me within the studio stuff. But also, I think what's important for me is personal care. I need this to do everything else.

Fighting for the adequate care I need to survive as a human and exist is paramount. And that's been a constant struggle because I'm constantly being assessed yearly to justify why I need carers and support. That takes energy.

But I've managed to secure funding for me to have a certain amount of hours for my personal care, which enables me to get up, get washed, get dressed, etc. This gave me space to live and not worry about whether I had enough hours of care support to cover me so I could use the toilet as much as I needed, etc. This has been paramount in my having the capacity to find that balance to practice as an artist, but also continually access services.

The transport services for work or study trips are limited to one destination a day, that's ridiculous! Are you serious!!? I think we need more advocacy and support. I think we need more advocacy to make the workplace accessible and inclusive.

It sounds like Finland is stuck in the 50s and the 60s, as it was in the UK, which is alarming because the everyday person would not know that. Being penalized, or the fact that they're removing that you can't earn 300 euros while on below minimum wage benefits they give you, is inhumane. Again, it's sad to say, but when this type of life experience doesn't affect people making these decisions, or able-bodied people, then it's not their concern really. It's not important to them.

Disability service reform in Finland sounds horrendous! And something that is written or promised, the reality is a different story. The phrase "things that belong to ordinary people" sounds like it could mean anything or nothing. But that sounds really medicalized, outdated, problematic, and dangerous. Just focusing on the care of an individual rather than the needs of the individual. Don't get me wrong, it has a place, but that's not what we need.

Selling ad space for our livelihoods, that's hilarious. I think that's a piece of work in itself, a performance piece. I definitely would be up for that.

Who doesn't like ice cream?

I prefer sorbet, a lemon and basil sorbet. I know that sounds quite bougie, ha.

As for an extra limb, that's a hard one for me. Um... I'm not sure if I want an extra limb. I think I would like a wheelchair that could climb up and down the stairs instead. I know they have ones now that do that, but they're totally out of reach for most people. I think for me, that would give me so much more access to different places. I can count a good 60, 70% of shops or places I can't get into because of steps. And a lot of these places see no reason to make reasonable adjustments.

So, I think if I could get into these places, I could be a bit of a troublemaker and point out that they need a ramp or a lift to make it accessible to everyone.

I think humour is a gift. It gives people a way in to think and engage with difficult topics. Comments are a clear indicator of how impactful and visceral your work is. I feel the comment, "We are all a little disabled," is cultural appropriation too.

It's important to keep pushing those boundaries!

I hope you have a lovely weekend. Take care.

All the best,

Chris.

14/01/2025

Dear Chris,

How are we today? Thriving, surviving, wading.

Weather: Sorbet-like slush on the ground, but it tastes neither like lemon nor basil. What a let-melt-down! We don't have sunlight for those flavors yet (sunset 3:47 PM). My basil is practicing toe touches on the windowsill, and my son's lemon tree—fragrant in the endless summer nights—is indoors and leafless.

I was happy to get your letter! We've sketched out many concepts that should be pushed forward—through politics, art, or a bit of both!

1. Skating in a power wheelchair. Please count me in! Back in school, I was excused from skating to avoid fractures. I spent winter sports classes watching others glide across the ice. With a power chair, I'd be brave enough to try—though not over curbstones!

2. Advertising on assistive devices or the body. Could we turn this into a workshop? I'd love to advertise "Humpty Dumpty Eggs" or "Crispy Meringues" (I've thought about starting a funeral business with an artistic twist later in life. Meringue would be the perfect name for it too!)

3. Accessibility in stores—crucial! I suggested to Rosette (a Finnish network of women with disabilities) that we print cards to jot down accessibility failures that could be tied with rosette ribbons to problem areas—like store door handles (though that won't help much if you can't even reach the door...).

4. A ranking of top-tier ridiculous disability regulations! LOL! Could we compare the UK and Finland? This could go viral. In Helsinki, disability transportation can no longer stop for 10 minutes if you're on your way to work, no picking up packages from lockers or grabbing a salad for lunch... Can you drop off kids at daycare on the way?

5. Recognizing "artist" as a profession in disability services. Some projects use artistic expertise to solve societal or business challenges. What if we insisted that disability services hire disabled artists at decision-making levels? Or set up artist residencies in social service offices?

6. International protest campaign! Environmental movements have succeeded with their sit-in street campaigns. Sprawling in front of parliaments and ministries to spend some quality "Crip time?"

7. The style and affordability of assistive devices. I read about a company that developed a decent 3D-printable prosthetic hand in a garage. The design is Open Access, and through a network, those in need can find a local company with a 3D printer—and possibly a sponsor for the materials. Admirable, but assistive devices should be free and automatically provided worldwide, so people could focus on thriving. Could this be visualized in a photo series?

8. Trust in receiving enough adequate assistance and care. The way applications demand we describe ourselves—focusing on our difficulties—isn't psychologically healthy. How does it shape self-image to constantly pitch our "faults" to authorities, even from childhood? (Hello, I'm Jenni-Juulia, with blue scleras, a curved back, pigeon chest, walking with a crutch, unable to lift heavy objects). Literary/Oratory arts? Poetry?

9. Laughing our way across the street. What if we pulled a bureaucrat in an office chair behind a power chair while crossing the street?

10. Let the reader of this booklet develop their own ideas 😊

The exhibition title: When I Grow Up... sarcastically refers to Marjatta Kurenniemi's fairytale The Girl Who Wanted to Grow Smaller. It's about a girl who, when reminded by her mother to eat, snaps back that she wants to grow smaller. When she grows tiny enough to bathe in a teaspoon, the president proposes that everyone start wishing for the girl to grow bigger—so that the "barrel of wishes" by Lady Fortuna would only have one wish to fulfill.

I genuinely thought that like-mindedness was a good thing—and that I'd grow up one day. Well, I still think it would be nice if everyone agreed with me on things I care about—ha ha. Accessibility, human rights, equality, inclusion, sufficient income for all, the ability to control one's own life, love, and peace. But let's not get into details 😊. Physically, I shrink year by year as my vertebrae collapse. My mother puts it more bluntly: my nastiness is getting more concentrated.

The second part of the title refers to being treated like a coat rack. People hang all sorts of things on a disabled person: prejudices, expectations, hospital gowns, an office-only worker's jacket, a bib to catch drool—but never a ceremonial sash, or astronaut gloves. Though superhero capes, yes. As Stella Young famously said, for simply remembering our names.

11th artwork idea could be a broken coat rack with spring hooks. When outdated beliefs, medical myths, ableist language, or violence are hung on it, the hooks bend and drop the burden. I'm a bad coat rack, forgetting my role, refusing to stay in the assigned place.

Thank you deeply for this correspondence Chris! I call my practice: Political Disability Arts, which addresses human rights issues and is inspired by societal discussions with colleagues and audiences. It's fueled by shared experiences, like we did here. You called it fuel to react, right? I didn't respond to your earlier suggestion to raise a toast—cheers to activist fuel!

Warmly!

Jenni-Juulia

16/01/2025

Hi Jenni-Juulia,

Thank you for an exciting and interesting email, dialogue and exchange.

Our ideas have been thought-provoking, not only for me but I hope for the readers.

It's always nice to conversate with other people who are passionate about accessibility, human rights, along with having great humour.

I'm excited at the possibility of us collaborating in the future.

I think we have interesting ideas that we can bring to life.

Let's continue to push the boundaries and challenge the idea of best practices and inclusion for all of us.

All the best for this exhibition, and let's continue our dialogue.

Warmest regards,

Chris

17/01/2025

Hi Chris,

It was such a pleasure to share thoughts, ideas - and politics with you.

Thank you for being my sharp and brilliant pen pal!

I was truly having a lot of fun, the way it is possible in activism even when the topics are life-death serious.

Hopefully this was just a start for provoking projects in the future. Fruitful brainstorming.

There is so much to do in this world and the victories already achieved in human rights work can be quickly lost if we don't keep them in the spotlight.

Wishing you inspirational - can I already say - Spring! (what you believe can happen :-)

Looking forward to working with you again!

Warmly,

Jenni-Juulia